# Law Drafting Instructions: Assisted Dying Law

## Contacts

Ministerial Sponsor: Minister for Health and Social Services Date of Instructions: 15 November 2024 Instructing Officer: Senior Policy Officer Legal Adviser: Law Officer's Department

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# 1. Introduction

- 1. Assisted dying is where a person with a terminal illness, who is experiencing or is expected to experience unbearable suffering, chooses to end their life with the help of a medical professional. Assisted dying in Jersey will only be permitted in certain limited circumstances that will be set out in law.
- 2. On 22 May 2024, the States Assembly ("the Assembly") voted for the Council of Ministers' proposition requesting the Minister for Health and Social Services to:
  - bring forward primary legislation that permits assisted dying in Jersey for those with a terminal illness
  - establish an assisted dying service in accordance with the essential provisions and safeguards set out in the proposition.
- 3. This paper sets out instructions to the Legislative Drafting Office (LDO) for the preparation of that assisted dying law.

4. It is envisaged that a draft assisted dying law will be debated by the States Assembly before the end of 2025, and that following an 18-month implementation period, the law would come into effect in 2027. As discussed, informally with the LDO, the anticipated timetable is as listed below, noting this may be subject to change should any stage of the drafting and review process take longer than anticipated:

Date	Task/activity
9 September 2024	draft Law Drafting Instructions (LDI) to LDO and
	Scrutiny Assisted Dying Review Panel
9 September – 8 October 2024	Scrutiny consideration of LDI
October/November 2024	LDI formally issued to LDO
September to c. 15 January 2025	LDO prepare first working draft of law
January – April 2025	Process of revisions and refining draft law, including sharing draft of law with key stakeholders (Jersey Care Commission and UK professional regulatory bodies)
April 2025	Revised draft agreed and shared with Scrutiny Panel and Scrutiny feedback on draft law
May 2025	Law Officers Department to review draft law, including advice on European Convention on Human Rights compliance
June – July 2025	Ministerial sign-off on draft law
By end of July 2025	Lodge Report and Proposition on draft law
July – November 2025	Lodging period
Late November 2025	Debate on draft law
Privy Council Review	Registration of law in Royal Court with establishing articles* to come into force on Registration
December 2025 (depending on Privy Council review timeframe) – May 2027	Implementation period
June 2027	Law brought into effect by an Appointed Day Act

\* *Establishing Articles* are the Articles of the Law which will need to be brought into force on registration of the Law in the Royal Court, for example the Articles that provide for the Minister to stand up the Assurance and Delivery Committee, and for the Assurance and Delivery Committee to deliver, during the Implementation period, the functions and activities necessary for the law to come into full effect (for example, develop the training programme, establish the register of assisted dying practitioners and register those professionals). Matters related to this will follow in separate instructions on Commencement.

## Background

- 5. In November 2021, the States Assembly agreed 'in principle' that assisted dying should be allowed and that arrangements should be made for the provision of an assisted dying service (P95/2021) but that, prior to the preparation of the law drafting instructions, detailed proposals should be brought back to the Assembly.<sup>1</sup>
- 6. The 2021 debate on assisted dying was informed by recommendations of the Jersey Assisted Dying Citizens' Jury.<sup>23</sup>
- Following the 'in principle' decision in 2021, detailed proposals for assisted dying in Jersey were developed, these were informed by: <sup>4</sup>
  - establishment of a Professional Leads Working Group<sup>5</sup>
  - engagement with key stakeholders, including the Jersey Care Commission and the UK professional regulatory bodies
  - discussion with experts in other jurisdictions where assisted dying is permitted
  - 2 phases of public consultation<sup>67</sup>
  - an ethical review<sup>8</sup>
- 8. In May 2024, the States Assembly voted to approve the proposition on detailed proposals for assisted dying, for those with a terminal illness only and to proceed to law drafting on that basis.<sup>9</sup>

## Principles of assisted dying

- 9. The principles that underpin the assisted dying proposals are described for information only. It is not intended that the principles are set out on the face of the assisted dying law, except for the principle that assisted dying is not suicide [see in additional drafting instructions to follow].
- 10. The assisted dying proposals are underpinned by the following principles:

<sup>&</sup>lt;sup>1</sup> <u>P.95-2021.pdf (gov.je)</u>

<sup>&</sup>lt;sup>2</sup> <u>Citizens' Jury on assisted dying in Jersey (gov.je)</u>

<sup>&</sup>lt;sup>3</sup> Final Report from Jersey Assisted Dying Citizens' Jury (gov.je)

<sup>&</sup>lt;sup>4</sup> Assisted dying in Jersey (gov.je)

<sup>&</sup>lt;sup>5</sup> <u>Assisted Dying working group TOR.pdf (gov.je)</u>

<sup>&</sup>lt;sup>6</sup> Public engagement summary report on assisted dying in Jersey (gov.je)

<sup>&</sup>lt;sup>7</sup> <u>Assisted dying in Jersey consultation (gov.je)</u> and <u>Assisted Dying in Jersey Phase 2 Consultation Feedback</u> <u>Report (gov.je)</u>

<sup>&</sup>lt;sup>8</sup> Assisted Dying in Jersey Ethical Review Report (gov.je)

<sup>&</sup>lt;sup>9</sup> p.18-2024.pdf (gov.je)

i. <u>Autonomy and choice</u> – a person is entitled to genuine choice when determining their end-of-life care and treatment. Their autonomy to make the decisions that are right for them should be respected. It is already the case that some people refuse care and treatment at end of life, whether on religious grounds or to avoid what they deem to be a protracted dying process, whilst others make advanced directives setting out their refusal of treatments or interventions such as resuscitation.

Some people will choose an assisted death because they want to exercise a degree of control over the end of their life and any associated suffering. This is a legitimate choice.

ii. <u>Assisted dying is a voluntary, clear, settled and informed wish</u> – a person requesting an assisted death should only do so if they wish to end their life, and that wish must be free from coercion. Nobody should feel pressurised by family, friends or by wider society to choose, or not to choose an assisted death.

In making their decision, people will consider a lot of different factors, one of which may be the distress felt by family / friends if the last weeks of their life involve suffering. This is a legitimate consideration, one with which people currently grapple when considering their care options.

The law, and the assisted dying process provided for in law, must provide safeguards to help ensure that a person's wish is free from coercion or pressure but, in doing so, it must be recognised that a voluntary wish, that is freely made, may be influenced by our love and concern for others.

iii. <u>Palliative and end of life care services</u> – assisted dying does not replace palliative care and end-of-life care services. A person approaching the end of their life or living with serious illness should be provided the care and treatment they need to maximise their quality of life and minimise any suffering or distress. Assisted dying is an additional choice that some people may make because they want more control over the manner and timing of their death. In jurisdictions where assisted dying is permitted, including Canada, Australia and New Zealand, the majority of people requesting an assisted death are also receiving palliative care (82.8%, 82.2% and 76.2% respectively).<sup>101112</sup>

Any person seeking an assisted death should be making a real choice. They should not choose an assisted death on the basis that they cannot access – or believe they cannot access – high quality end-of-life or palliative care services.

Should the Assisted Dying Law be approved by the Assembly, it is envisaged that that law will be brought into force by an Appointed Day Act and that before

<sup>&</sup>lt;sup>10</sup> Second Annual Report on Medical Assistance in Dying in Canada 2020 - Canada.ca

<sup>&</sup>lt;sup>11</sup> Voluntary Assisted Dying Review Board report of operations: January to June 2021 (safercare.vic.gov.au)

<sup>&</sup>lt;sup>12</sup> Assisted Dying Service – Ngā Ratonga Mate Whakaahuru. Registrar (assisted dying) Annual Report to the Minister of Health

making that Act Members must be satisfied that decision taken in the 2023 Government Plan to provide for additional investment in end of life and palliative care is supporting improvements in quality and availability of those services.

In addition, consideration is being given to placing a statutory duty on the Minister for Health and Social Services to provide palliative care and end of life care as part of proposed Adult Safeguarding Law that is currently in development.

iv. <u>Health professionals</u> – the law will provide that no health or care professional can be compelled to participate in the assessment, approval or delivery of an assisted death. The right of any person to conscientiously object and decline to participate does not, however, extend to obstructing the choice of a person who wishes to have an assisted death. This means that a care professional, who is providing care to a patient who wishes to seek information about assisting dying, will be required signpost a patient to the assisted dying service.

Professionals who participate in the assisted dying process must have access to support services that help them process and reflect on the emotions associated with assisting someone to die.

- v. <u>Assisted dying is not suicide</u>– whilst both assisted dying and suicide result in intentionally ending one's own life, when a person dies by suicide it is a lonely act, carried out outside of a legal framework, and is accompanied by mental and physical pain and fear. Suicide invariably leaves behind a legacy of stigma and irresolvable grief for family / friends. Assisted dying can be the exact opposite, it provides a safe, calm and considered environment in which a person most often with the support of their family / friends can end their life and associated suffering. The law will set out that assisted dying is not suicide [see in additional drafting instructions to follow].
- vi. <u>Family and friends</u> family members and close personal contacts will be supported throughout the process, including being supported to openly discuss their loved one's preferences and choices. Ultimately, however, the choice of an assisted death can only be made by the person requesting it. The family cannot request an assisted death, nor can they block the person's wishes.

## Assisted dying law

- 11. The purpose of the assisted dying law will be to:
  - give persons who have a terminal illness the option of lawfully requesting and, if they meet certain criteria set out in law, receiving medical assistance to end their lives; and
  - to establish a lawful process, with appropriate safeguards, for assessing and determining whether a person who has requested an assisted death meets the criteria set out in law; and

- make it lawful for a health and care professional to assist a person to end their life, in accordance with the processes and safeguards set out in the law.
- 12. The law will need to address all the matters set out below, each of which is addressed in a separate section to these instructions:
  - Eligibility criteria
  - Establishment of the Jersey Assisted Dying Service including the establishment of an Assisted Dying Assurance and Delivery Committee
  - Health and care professionals' involvement in assisted dying Including defined roles set out in the law, and the requirement to register as an assisted dying practitioner
  - The right to refuse to participate in assisted dying
  - The assisted dying process
  - Regulation and oversight of assisted dying

## Note: References to Orders

13. These instructions make reference to the power of the Minister to prescribe matters by Order (for example, matters related to the content of assisted dying forms). The Law Drafting Officer is asked to make provision for the making of such Orders, having determined that such matters should be prescribed by Order.

## Terms used

Below is an explanation of the terms used in these instructions. The Law Drafter may deem that other terms need to be used for the purposes of the Law:

- Administering Practitioner the doctor or registered nurse (level 1) who will directly administer the assisted dying substance or support the person to self-administer the substance. Works within the Jersey Assisted Dying Service.
- **allied health professional** A qualified person who practises one of a wide range of health-related professions (e.g., Physiotherapists, Speech and language therapists, Occupational therapists).
- **assessing doctors** the Coordinating Doctor and the Independent Assessment Doctor (plus the Second Opinion Doctor, where relevant) are collectively referred to as "assessing doctors". They will assess the person who has requested an assisted death to determine if they meet the statutory criteria. They work within the Jersey Assisted Dying Service.
- assisted death where a person has been assessed and approved as eligible for an assisted death in accordance with the law, is supported to either self-administer the assisted dying substance or is administered the substance by an assisted dying practitioner resulting in their death, is an assisted death
- **assisted dying** assisted dying is where a person with a terminal illness, who is experiencing or is expected to experience unbearable suffering, chooses to end their life with the help of a health and care professional. They may only do so if they have been approved for an assisted death, having been assessed as meeting all the eligibility criteria set out in law.
- Assisted Dying Assurance and Delivery Committee The Committee which oversees establishment and operations of the Jersey Assisted Dying Service, including development of training programmes, professional guidance and non-professional guidance.
- Assisted Dying Person Record a single record detailing all information about a person's request for an assisted death and the assessment, approval, planning and delivery processes associated with that assisted death, including all required forms.
- **assisted dying practitioner** any professional who is registered with the Jersey Assisted Dying Service, having met all registration requirements including mandatory training. This includes assessing doctors, Administering Practitioners, pharmacy professionals and all members of the multidisciplinary team.

It does not include the Care Navigator or the Assisted Dying Registered Medical Practitioner (ADRMP)

- Assisted Dying Registered Medical Practitioner (ADRMP) a medical practitioner who is registered with the Jersey Assisted Dying Service. All assisted deaths must be certified by an ADRMP.
- **assisted dying process** the assisted dying process involves the 8 steps set out in law that covers the request, assessment, approval, planning, provision of an assisted death and the required actions after an assisted death:
- Step 1 First formal request
- Step 2 First assessment
- Step 3 Independent assessment
- Step 4 Second formal request
- Step 5 Administrative review (approve or refuse)
- o Step 6 assisted death care planning
- o Step 7 assisted death delivery
- Step 8 after an assisted death
- Assisted Dying Review Panel Panel established to undertake a post-death review of every assisted death, to determine proper adherence to professional guidance (as distinct from non-professional guidance) and legislation.
- Assisted dying substance the drugs/medications used for the purpose of causing the person's assisted death. The combination of drugs/medications used will be approved by the Assisted Dying Assurance and Delivery Committee in the Authorised Drug Regimen
- Authorised Drug Regimen the combination(s) of drugs/medications, that have been approved by the Assisted Dying Assurance and Delivery Committee to be used as the assisted dying substance.
- **Care Navigator** non-clinical staff who will support the person requesting an assisted death and support the Coordinating Doctor to coordinate the process. Initial point of contact for information and enquiries into the Jersey Assisted Dying Service. They must have done the mandatory assisted dying training, but they do not need to be registered with the Assisted Dying Service because they are not clinical staff.
- Connected person opinions an opinion, requested by an assessing doctor and provided by a third party who is connected to the person, this could be a family member, friend, neighbour, work colleague etc. The person providing a connected person opinion may be a professional in their own right (i.e., they may be a nurse) but they are being asked their opinion on the basis of their personal knowledge / relationship with the person, not in their professional capacity. The purpose of the opinion is to provide information or insight that may support the assessing doctor's determination of eligibility. (These are distinct from *Professional supporting assessments and opinions* see below)

- **Coordinating Doctor** the doctor who: undertakes the first assessment of the person who has requested an assisted death, coordinates the whole assessment process; makes the decision to approve or refuse the request. Works within the Jersey Assisted Dying Service.
- **conscientious objection** Conscientious objection is when a person chooses not to participate in a legally and clinically appropriate treatment or procedure because it conflicts with their personal beliefs and values. A person will have the right to refuse to participate in assisted dying (including if that is a conscientious objection) under the assisted dying law.
- **decision-making capacity** refers to a person's ability to make day-to-day decisions about legal, medical / health care, financial and personal matters. In this context it specifically refers to the person's capacity to make the decision to request or have an assisted death.
- doctor -the term doctor has been used in this report for ease of understanding. It
  refers to a medical practitioner who is registered with the UK's General Medical
  Council (GMC) and with the Jersey Care Commission. This may include a general
  practitioner (GP), middle grade doctor or a consultant.
- **health and care professional** any doctor, registered nurse, social worker, allied health professional or any person employed to provide care to a person in Jersey, including residential and domiciliary care.
- Health and Community Services Department (HCS) The Government of Jersey's Health and Community Services Department, overseen by the Minister for Health and Social Services. Responsibilities of the Department include the provision of a wide array of hospital services, social care and support in the community, as well as the monitoring and improvement of service quality and the education and development of health and care professionals.
- Independent Assessment Doctor the doctor who undertakes the second, independent assessment of the person who has requested an assisted death. Works within the Jersey Assisted Dying Service.
- **involved professional** is an assisted dying practitioner who is involved in the assisted dying process for a specific individual. This may include the assessing doctors, the Administering Practitioner, the pharmacy professional and members of any MDT convened for that specific individual. It does not include the Care Navigator or ADRMP
- Jersey Assisted Dying Service provides access to assisted dying in Jersey. The Jersey Assisted Dying Service will be managed and delivered by Health and Community Services Department (HCS). [See section 3 – Jersey Assisted Dying Service]

- Jersey Care Commission (JCC) Regulates and inspects health and care services for both adults and children in Jersey. The JCC also registers and regulates health and care professionals in Jersey. The JCC will regulate the Jersey Assisted Dying Service [see section 8 – Regulation and oversight].
- **Multidisciplinary team (MDT) member** an MDT will be formed to support the assessment process for a person who requests an assisted death. In addition to the assessing doctors, the MDT may include a registered nurse (level 1), social worker and any relevant allied health professionals (e.g., a speech and language therapist)
- other attending practitioners and carers the term used to describe service providers who may be involved in care or treatment of the person who has requested an assisted death (for example, a domiciliary care provider, a community or hospital nurse, a GP) but who are not directly involved in the assisted dying request, assessment, approval or administration process (except for, where they are asked to undertake a supporting assessment, or provide information or advice to support an assessment or determination (and do not refuse to participate)
- **Pharmacy Professional** pharmacist or pharmacy technician who has registered with the Jersey Assisted Dying Service. Will prepare and dispense the substance used in assisted dying, will work within the Hospital Pharmacy.
- **physical medical condition** a broad term that includes all diseases, lesions, injuries, and disorders, but does not include mental illnesses.
- practitioner-administration / practitioner-administered denotes when a doctor or registered nurse administers / has administered the assisted dying substance which ends the person's life. This would usually be the administration of the assisted dying substance intravenously [see Step 7: assisted death delivery].
- **Professional guidance** professional guidance approved and made available to relevant persons by the Assurance and Delivery Committee. Professional Guidance must include the following (with a power for the Committee to bring forward other professional guidance, with the approval of the Minister, when the Committee determines it is necessary to do so):
  - 1. Right to Refuse and Conscientious Objection Guidance
  - 2. Appropriate Conversations Guidance
  - 3. Assisted Dying Person Record Guidance
  - 4. Assisted Dying Practitioner Registration Guidance
  - 5. Location Guidance
  - 6. Interpreting, Communication, Support and Advocacy Guidance
  - 7. Assessment Guidance
  - 8. Assisted Death Care Planning Guidance
  - 9. Prescribing and Dispensing Guidance

10. Assisted Dying Substance Administration Guidance

- 11. Assisted Dying and Organ Donation Guidance.
- Non-professional guidance guidance approved and published by the Committee, as listed below, with a power for the Committee to bring forward other non-professional guidance when the Committee determines it is necessary to do so. Adherence to non-professional guidance does not need to be determined by the Assisted Dying review panel:
  - o Guidance for Families and Carers
- **Professional regulatory bodies** –UK bodies that health and care professionals are required to register with, includes General Medical Council (GMC); Nursing and Midwifery Council (NMC); Health and Care Professions Council (HCPC) and General Pharmaceutical Council (GPhC).
- **Professional supporting assessments** *I* **opinions** an assessment of the person or an opinion, requested by an assessing doctor and provided by a relevant professional, in order to support that assessing doctor's determination of eligibility. The assessment or opinion itself is not a determination of eligibility. (These are distinct from *Connected person opinions* see above)
- **Registered nurse** the term registered nurse has been used in this report for ease of understanding. It refers to a registered nurse (level 1) who is registered with the UK's Nursing and Midwifery Council (NMC) and with the Jersey Care Commission.
- **Relevant forms** the forms completed by assisted dying practitioners and persons engaged in the assisted dying process:
  - 1. All Step Transition forms
  - 2. Information Sharing Consents form
  - 3. Initial Enquiry form
  - 4. First Formal Request form
  - 5. First Assessment Report form
  - 6. Second Opinion Assessment Report form
  - 7. Independent Assessment Report form
  - 8. Practitioner Transfer form
  - 9. Second Formal Request form
  - 10. Administrative Review (approve or refuse) form
  - 11. Refusal of Request form
  - 12. Assisted Death Care Plan form
  - 13. Assisted Dying Substance Dispensing form
  - 14. Final Consent and Review form
  - 15. Post-Assisted Death Administration form
- **Relevant professional** Any professional that the assessing doctor is of the opinion has the necessary experience or expertise to provide an opinion on any matter that the assessing doctor determines is relevant to support them to make a

decision as to whether the person meets the eligibility criteria. The professional may be based in Jersey or elsewhere. The professional may or may not have previously treated or provided care for the person being assessed. The professional may be a health and care professional, or any other professional that the assessing doctor considers relevant to provide advice or opinion to support them to make an eligibility determination.

- Second Opinion Doctor the doctor who undertakes a second opinion assessment if the person makes a request for a second opinion assessment and that request is accepted (a second opinion assessment may be requested after the first or independent assessment). Works within the Jersey Assisted Dying Service.
- Self-administer / self-administration denotes when a person takes / has taken the assisted dying substance themselves to end their life. This would usually be the ingestion of the assisted dying substance orally.
- **the person** refers to the person who has requested an assisted death. They are not referred to a patient or a client because, in some cases, they may be individuals who are not receiving treatment or care from a service provider.

# 2. Eligibility criteria

This section outlines the eligibility criteria for assisted dying and provides detail on the process for assessing each of the eligibility criteria

In this section, elements highlighted in grey, set out policy to be incorporated in the professional guidance, as opposed to covered explicitly by law. The information is included in these instructions for completeness and to help fully articulate the assisted dying process.

### Summary of eligibility criteria

Assisted dying will only be lawful where a person meets <u>all of</u> the following eligibility criteria. The person must meet the:

#### Health eligibility criteria

a. have been diagnosed with a terminal illness which is giving rise to, or is expected to give rise to, unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable and that terminal illness must be reasonably expected to cause the person's death within 6 months at the point of assessment or 12 months at the point of assessment in the case of neurodegenerative conditions

#### Age criteria

b. be aged 18 or over;

#### Residency criteria

c. be ordinarily resident in Jersey;

#### Nature of wish criteria

d. have a voluntary, clear and settled wish to end their own life, and that wish is informed

#### Decision-making capacity criteria

e. have capacity to make the decision to end their own life.

### Health eligibility criteria

- 14. For a person to be eligible they must have been diagnosed with a medical condition that meets all four qualifications below:
  - a terminal illness
  - that is giving rise to, or is expected to give rise to unbearable suffering
  - that cannot be alleviated in a manner the person deems to be tolerable, and
  - that is reasonably expected to cause the person's death within the specified timeframe.

## Qualification 1: a terminal illness

- 15. A 'terminal illness' refers to a diagnosis of a physical disease, physical illness or physical medical condition that is advanced and progressive and will cause death.
- 16. A person who has been diagnosed with more than one medical condition may be eligible for assisted dying, as long as at least one of those conditions meets the definition and qualifications of 'terminal illness'.
- 17. The criteria only apply to physical conditions and <u>do not include mental or psychiatric</u> <u>illness or disorders</u>. Neurodegenerative conditions such as Motor Neurone Disease and Alzheimer's disease would fall within the physical conditions criteria but to be eligible for assisted dying the person must have decision-making capacity [see also paragraph 121].<sup>13</sup>
- 18. Examples of mental and psychiatric illness or disorders which do not fall within the criteria as an eligible condition include anxiety disorders (for example, obsessive-compulsive disorders and phobias); depression, bipolar disorder and other mood disorders; eating disorders; personality disorders; post-traumatic stress disorder; psychotic disorders, including schizophrenia.
- 19. However, a person with a mental illness diagnosis should not be automatically excluded from being eligible for assisted dying if they also have terminal illness and they meet all the eligibility criteria. For example, a person who has been diagnosed with end-stage chronic obstructive pulmonary disease (COPD) (a physical medical condition) with a life expectancy of 3 months, who also has a diagnosis of depression, may be eligible but they must be assessed, in accordance with the process set out in law, as meeting all the criteria, including retaining their decision-making capacity

<sup>&</sup>lt;sup>13</sup> Metal illness, as recognised by international disease classification resources such as the Statistical Manual of Mental Disorders, Fifth Edition <u>Psychiatry Online | DSM Library</u> or Mental, behavioural or neurodevelopmental disorders states in the ICD-11 <u>International Classification of Diseases (ICD) (who.int)</u>

- 20. The term 'terminal illness' does appear in Jersey legislation in specific contexts, but it is understood that there is not a general application of the term 'terminal illness', nor a specific life expectancy timeframe associated with the term in Jersey law.<sup>1415</sup>
- 21. In assisted dying laws and proposed legislation in other English-speaking jurisdictions, the terminal nature of the person's condition is referenced as follows:

Jurisdiction	Phrasing used in assisted dying law
Victoria, Australia <sup>16</sup>	the person must be diagnosed with a disease, illness or medical condition that— (i) is incurable; and (ii) is advanced, progressive and will cause death;
Western Australia, Australia <sup>17</sup>	the person is diagnosed with at least 1 disease, illness or medical condition that — (i) is advanced, progressive and will cause death
Queensland, Australia <sup>18</sup>	the person has been diagnosed with a disease, illness or medical condition that— (i) is advanced, progressive and will cause death
New Zealand <sup>19</sup>	suffers from a terminal illness
California, USA <sup>20</sup>	a terminal disease - an incurable and irreversible disease that has been medically confirmed
Scottish Parliament - Assisted Dying for Terminally III Adults (Scotland) Bill	a person is terminally ill if they have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death.
UK Parliament Assisted Dying for Terminally III Adults Bill <sup>21</sup>	<ul> <li>a person is terminally ill if that person—</li> <li>a) has been diagnosed by a registered medical practitioner as having an inevitably progressive condition which cannot be reversed by treatment ("a terminal illness"), and</li> <li>(b) as a consequence of that terminal illness, is reasonably expected to die within six months.</li> <li>(2) Treatment which only relieves the symptoms of an inevitably progressive condition temporarily is not to be regarded as treatment which can reverse that condition.</li> </ul>

<sup>&</sup>lt;sup>14</sup> Income Support (General Provisions) (Jersey) Order 2008 (jerseylaw.je) – Article 6

<sup>&</sup>lt;sup>15</sup> Public Employees (Pension Scheme) (Membership and Benefits) (Jersey) Regulations 2015 (jerseylaw.je) – Article33

<sup>&</sup>lt;sup>16</sup> Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au)

<sup>&</sup>lt;sup>17</sup> Voluntary Assisted Dying Act 2019 - [00-00-00].pdf (legislation.wa.gov.au)

<sup>&</sup>lt;sup>18</sup> Voluntary Assisted Dying Bill 2021 (legislation.qld.gov.au)

<sup>&</sup>lt;sup>19</sup> End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 5 Meaning of person who is eligible for assisted dying or eligible person – New Zealand Legislation – Article 5

<sup>&</sup>lt;sup>20</sup> <u>Codes Display Text (ca.gov)</u>- see 4331.1 (r)

<sup>&</sup>lt;sup>21</sup> Assisted Dying for Terminally III Adults Bill [HL] (parliament.uk)- Article 2

(3) A person is not considered to be terminally ill solely by reason of:
(a) being diagnosed with a mental illness, within the meaning of the Mental Health Act 1983, or
(b) having a disability, within the meaning of section 6 of the Equality Act 2010

22. The policy intent is that the definition of 'terminal illness' in the assisted dying law would mean a person who has been diagnosed with a physical disease, physical illness or physical medical condition that is advanced and progressive and will cause death.

Qualification 2: that is giving rise to, or is expected to give rise to unbearable suffering

23. The person must either be experiencing unbearable suffering as a result of their terminal illness OR must have an expectation that their terminal illness will, before their death, give rise to suffering which they are likely to find unbearable.

Qualification 3: cannot be alleviated in a manner the person deems to be tolerable

24. There may be treatment options available that alleviate the condition or the suffering caused by the terminal illness to a degree, or that results in a longer life expectancy including the potential to extend life expectancy to more than 6 months (or more than 12 months in the case of neurodegenerative conditions), but the person may consider those treatment options too invasive, painful or debilitating to be tolerable – for example, a patient may decline chemotherapy because of the associated side-effects. The law should allow that a person always has the right to choose to decline treatment.

Making a determination as to whether the person has a terminal illness which is giving rise to, or is expected to give rise to, unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable

- 25. The law will not require the assessing doctor to determine whether the suffering is *unbearable* as this is entirely subjective. It will require the assessing doctor to be satisfied, to their best of their ability, that the person's own determination that they cannot bear their suffering / will not be able to bear the anticipated suffering, is, like their request for an assisted death, voluntary, clear, settled and informed.
- 26. The law will set out that the Assessing Doctor must be satisfied of the matters below:
  - the person has a terminal illness that is causing suffering, and
  - that the person deems that they cannot bear the suffering, and
  - that the suffering cannot be alleviated in a manner that the person considers tolerable, OR
  - the person has a terminal illness that is reasonably expected to give rise to suffering, and
  - that the person deems that they will not be able to bear the expected suffering, and
  - that the expected suffering cannot be alleviated in a manner that the person considers tolerable
- 27. The law should provide that an assessing doctor (whether a Coordinating Doctor, Independent Assessment Doctor, or Second Opinion Doctor) does not need to an expert or specialist in the condition / illness of the person. This is because the Assessing Doctor will either be capable of making a determination in relation to a person with that condition / illness, OR they will commission a supporting assessment / opinion from a professional who is.
- 28. The Assessing Doctor includes:
  - a. the Coordinating Doctor who must be satisfied of these matters before they sign the First Assessment Report Form
  - b. the Independent Assessment Doctor who must be satisfied of these matters before they sign the Independent Assessment Report Form
  - c. a Second Opinion Doctor (if relevant) who must be satisfied of these matters before they sign the Second Opinion Assessment Report form

Suffering

Presence and cause of suffering

- 29. Assessment Guidance will define suffering as including:
  - a. physical suffering (for example, pain) and / or

- b. mental suffering (for example, anguish associated with inability to carry out daily tasks or communicate due to the person's terminal illness), and /or
- c. suffering caused by the treatment provided for the terminal illness.
- 30. The assessing doctors must determine that either:
  - a. there is suffering (whether that is physical and / or mental suffering)
  - b. there is an expectation of suffering
- 31. They will make this determination based on their assessment of the person (and any supporting assessments) and their knowledge of the terminal illness and its likely impact on people. Key to this determination will be consideration of whether the person is suffering / likely to suffer or whether their claim of current suffering / stated fear of expected suffering arises from coercion. It must be the person who is articulating their suffering as opposed to any third-party articulating suffering / fear of suffering on their behalf (although the assessing doctors may seek opinion from third parties as required). [Note, this does not exclude the use of interpreters or communication support by the person to communicate.]
- 32. In most cases suffering or fear of expected suffering will be self-evident.
- 33. Having determined that there is suffering / expectation of suffering the assessing doctors must then determine whether that suffering arises from the person's terminal illness.
- 34. Suffering arising solely from the following will not satisfy the requirements under law even where the person has a terminal illness because the suffering does not arise from the terminal illness:
  - a. the person's living situation (for example, their relationship has just broken down)
  - b. generalised fears about the future (for example, concern about debt)
  - c. generally 'being tired of life'.
- 35. Causes of suffering may include:
  - a. the terminal illness itself and the impact of that terminal illness

A person has terminal lung cancer (their death is anticipated in 4 months). They are experiencing extreme discomfort and severe physical pain. The person would be eligible under Route 1 because they have a terminal illness, and their physical suffering arises directly from that terminal illness.

b. the treatment provided for the terminal illness

A person with stage IV breast cancer is experiencing significant side effects from chemotherapy including severe fatigue, nausea and vomiting and repeated infections, all of which cause suffering, alongside an expectation of further physical suffering close to the end of their life due to the progression of the cancer. With a life expectancy of less than 2 months

c. complications of the person's treatment for their terminal illness

A person received has chemotherapy treatment for leukaemia. A significant long-term side effect of the chemotherapy was chronic heart failure. The heart failure is giving rise to shortness of breath and exhaustion, as well as severe pain and in inability to walk or leave the house, all of which contributed to the person's physical and mental suffering.

The person may be eligible depending on the prognosis for both/ either the leukaemia or the associated with the heart failure – i.e. if either result in life expectancy of 6 months or less.

- 36. Current mental suffering that is arising (as opposed to mental suffering that could potentially arise in the future) from the following may satisfy the requirement under law in the absence of physical suffering where the person has a terminal illness, and the assessing doctor determines that mental suffering arises from that terminal illness:
  - a desire to relieve distress over a loss of autonomy (for example, inability to undertake day-to-day tasks such as toileting)
  - fears about their pending death / the suffering associated with that pending death
  - c. desire to control the circumstance around their death
  - d. fears about the burden on family / friends.
- 37. Suffering that arises from mental illness alone will not satisfy the conditions of the law, but a person with a mental illness may be eligible for an assisted death if they also have terminal illness which is giving rise to suffering.
- 38. The presence of mental illness (such as depression) is not uncommon in people at end of life. The Coordinating Doctor will need to determine if any mental anguish or suffering a person is experiencing arises from:

a. mental illness alone

## b. a combination of their mental illness and physical condition.

39. Where there is uncertainty as to the cause of mental suffering, the Coordinating Doctor must make a referral for determination to a relevant professional with training and skills to support determination of the matter. This may include a psychiatrist or psychologist.

## Person A

Person A has a diagnosis of Schizophrenia. This is causing them to experience mental anguish and suffering. However, they <u>would not be eligible for assisted</u> dying as they do not have a diagnosis of a terminal illness.

## Person B

Person B has been diagnosed with end-stage chronic obstructive pulmonary disease (COPD) (a terminal illness) with a life expectancy of 3 months; they also have a diagnosis of depression.

Person B's request for assisted dying would likely be approved. They <u>would be eligible</u> as they have a terminal diagnosis and have demonstrated to the Coordinating Doctor that their unbearable suffering is, at least in part, a result of their COPD as they can no longer carry out basic day-to-day tasks, have difficulty speaking, and feel anguish about being a burden to others.

## Is the suffering bearable?

- 40. As set out above, the law will provide that the assessing doctors must determine that there is suffering / expected suffering (whether physical and / or mental) and they must determine the cause of that suffering / expected suffering but the law will not require them to determine if the suffering / expected suffering is unbearable.
- 41. Suffering is a subjective experience, as is fear of anticipated suffering. Different people experience suffering or fear of suffering in different ways, and hence it is only the person who can determine what that person believes they can bear.
- 42. The law will require the assessing doctors to:
  - a. document the person's own determination of whether they can bear their current suffering or the expected suffering, and

- be satisfied, to their best of their ability, that the person's own determination is a voluntary, clear, settled and informed determination (i.e., it is free from coercion).
- 43. As part of this, the assessing doctors will need to be satisfied that the person understands that:
  - a. suffering is not fixed, the physical pain and the mental, emotional, social, spiritual or existential anxiety and suffering associated with a terminal illness may fluctuate
  - a person's ability to tolerate suffering may be impacted by life events or circumstances, for example:
    - the emotional joy associated with the birth of a grandchild may make the suffering more tolerable for a period of time
    - the fear of disease progression and deteriorating quality of life may be greater than current quality of life
  - c. fear of expected suffering may be worse than the actual suffering (the physical pain may be more bearable than envisaged; the mental anguish associated with fear of loss of autonomy may be worse than the loss of autonomy).
- 44. Where the person is not currently experiencing unbearable suffering but the terminal illness is expected to give rise to suffering, it is clearly the case that the assessing doctors cannot determine if the person can bear future suffering (unlike current suffering which they can often directly witness) hence they can only be satisfied that the person's determination of their own ability to bear future suffering is a voluntary, clear, settled and informed determination.
- 45. It must be recognised that the ability of a person to bear suffering may be multifactorial, arising from:
  - a. a combination of physical and mental suffering, or
  - b. it may be that suffering arising from a longer term physical medical condition, which the person has found to be bearable to date, is compounded by a terminal illness and the associated treatment, example below:

A person had a stroke five years ago which left them with paralysis on one side of their body. They generally adapted well to life but have subsequently been diagnosed with cancer – the impact of the stroke on the person's ability to move and easily communicate, combined with the side-effects of their cancer and the associated treatment has led to unbearable suffering.

Qualification 4: that is reasonably expected to cause the person's death within the timeframe specified.

- 46. The specified timeframe is that the terminal illness must be reasonably expected to cause the person's death within 6 months at the point of assessment by the assessing doctor, or within 12 months at the point of assessment in the case of neurodegenerative conditions.
- 47. Whilst it is acknowledged that doctors cannot be exact when predicting an individual's life expectancy, reasonable predictions can be made, based on statistical / clinical data available for most diseases. As with all medical prognoses, different people will have different disease progression trajectories. The law will therefore provide that the assessing doctors may make an assessment of life expectancy which they determine is reasonable based on their medical knowledge and their examination / assessment of each individual person.
- 48. The 6-month timeframe for the majority of terminal illnesses accords with legislation in a number of other jurisdictions, including New Zealand, US states (such as Oregon, California and Vermont) and Australian States (including Victoria, Western Australia and New South Wales).

#### 12-month timeframe for neurodegenerative diseases

- 49. The law will provide for a 12-month specified timeframe for people who have a terminal illness that is a neurodegenerative disease which, due to the nature of the disease, is likely to see a significant deterioration in quality of life and associated potential for unbearable suffering significantly before the person reaches the point of having six months life expectancy.
- 50. 'Neurodegenerative diseases' are a group of slowly progressing irreversible conditions characterized by neuronal death and subsequent atrophy of certain areas of the brain, they include Motor Neurone Disease (MND), Huntington's disease and Parkinson's disease.
- 51. Alzheimer's Disease is a form of dementia and is also a neurodegenerative disease, however, a person whose dementia is so advanced that they are likely to die within the 12-month timeframe would be highly unlikely to retain the necessary decision-making capacity to request assisted dying. Therefore, it is the combination of eligibility criteria that would likely exclude a person with only a diagnosis of Alzheimer's disease from being eligible for assisted dying.
- 52. This does not mean people who have dementia cannot access assisted dying if they also have a terminal illness. For example, a person who retains decision-making capacity in the early stages of Alzheimer's disease with terminal cancer may access assisted dying.

53. The inclusion of a 12-month life expectancy for neurodegenerative diseases mirrors provision in Australia (New South Wales, South Australia, Tasmania, Victoria and Western Australia).

## Making a determination as to life expectancy

- 54. The law will set out that the Assessing Doctor must be satisfied, that the person's terminal illness is reasonably expected to cause the person's death within 6 months of the date of signing the assessment form, or where the person's terminal illness is a neurodegenerative condition, within 12 months of the date of signing the form
- 55. Assessing Doctor includes:
  - a. the Coordinating Doctor being satisfied before they sign the First Assessment Report Form
  - b. the Independent Assessment Doctor being satisfied before they sign the Independent Assessment Report Form
  - c. a Second Opinion Doctor (if relevant) being satisfied before they sign the Second Opinion Assessment Report form
- 56. It is acknowledged that doctors cannot be exact when predicting an individual's life expectancy, therefore the law will provide that doctors may make an assessment of expectancy which they determine is reasonable based on their medical knowledge and their examination / assessment of each individual person.
- 57. For clarity, the Assessing Doctor does not need to determine the person's precise life expectancy in days or months, they only need to be satisfied the person meets the life expectancy criteria, i.e., they are satisfied that the person's life expectancy is, at the point of assessment:
  - 6 months or less, or
  - 12 months or less, in the case of neurodegenerative conditions) at the point of assessment, or
  - 14 days or less (in cases where the minimum timeframe requirements are to be disapplied [see section 5 assisted dying process overview].
- 58. The Assessment Guidance will set out that in order to make a determination of life expectancy, the Coordinating Doctor will review the person's medical records (if consent had been obtained) and consider their medical history and prognosis.

59. Assisted dying will only be permitted for adults – i.e., a person must be aged 18 years or over at the time they make their first formal request for an assisted death

## Assessing the age eligibility criteria

- 60. The law will set out that the Coordinating Doctor must be satisfied, before they sign the First Assessment Report Form, that the person was aged 18 or over at the time of making their First Formal Request.
- 61. There is no requirement for the Independent Assessment Doctor to re-assess the person's age during the Independent Assessment. The Coordinating Doctor's determination that the person meets the age criteria is presumed to stand as correct.
- 62. A person cannot request a second opinion assessment on the matter of residency.
- 63. In most cases a formal proof of age check will not be required as it will be selfevident that a person requesting assisted dying is aged 18 or over.
- 64. However, if a proof of age check is required for the Coordinating Doctor to be satisfied that person must be asked to provide the relevant Information Sharing Consent as part of the first formal request process allowing age to be verified with other Government Departments and / or agencies (if the Consents have not already been provided) or the Coordinating Doctor may require the person to provide photographic proof of age. Proof of age can be in any form the Coordinating Doctor determines is acceptable for them to be satisfied as to the person's age (e.g.: passport or driving licence)
- 65. If person does not meet the criteria on grounds of age, the law will provide that the Coordinating Doctor must determine they are not eligible. The person may, however, make a new First Formal Request once they have turned 18.
- 66. The Assessment Guidance will set out that in most cases, any checks on proof of age will be undertaken prior to the First Assessment, where the person has provided consent to do so.

## Residency criteria

- 67. For the purposes of the law, a 'Jersey resident' means a person who has been ordinarily resident in Jersey for a minimum of 12 consecutive months in the period immediately before they make their first formal request for an assisted death.
- 68. The 12-month time limit is intended to discourage 'death tourism' (i.e., people travelling to Jersey specifically for the purposes of accessing the assisted dying service) whilst not unduly preventing access to assisted dying for those who have moved to the Island more recently.

- 69. Ordinarily resident means a person who lives in Jersey and spends all their time here except for short visits abroad on business or holiday. It does not include people who temporarily live in Jersey for work or for study or other purposes, or who are on holiday in Jersey.
- 70. The term 'ordinarily resident' does appear in several Jersey laws in specific contexts, but it is understood that there is not a general definition of the term 'ordinarily resident', nor a specific timeframe associated with the term.
- 71. The requirement to have been ordinarily resident in Jersey for at least 12 consecutive months immediately before making a first formal request will apply to all people. A person who is, for example, Jersey born but has been living elsewhere cannot bypass the 12-month ordinarily residency criteria even if they are entitled to free health care under Health and Community Services Department's existing Residents and Non-Residents Charging policy HCS's charging policy (or any other equivalent policy that may be in place at the time of their assisted dying request).<sup>22</sup>
- 72. It is understood that an implicit feature of 'ordinarily resident' as set out in the Control Of Housing And Work (Jersey) Law 2012: Residential And Employment Status – Policy Guidance - is that person who is placed in a residential, care or treatment facility outside of Jersey, by the Government of Jersey because on-island services cannot meet that person's needs, would be treated as if they were ordinarily resident in Jersey.<sup>23</sup> This provides for the circumstance, for example, where an individual has specialist long-term care needs which cannot be provided in Jersey or a looked after child cannot be cared for on-island. In such situations an off-Island placement will be provided, normally in the UK, which is arranged and funded by the Health and Social Services Department or the Department for Children, Young People, Education and Skills. The time spent outside Jersey in these circumstances will continue to be included as ordinary residence in Jersey. this is similar to the provision in Long-Term Care (Residency Conditions) (Jersey) Regulations 2013. However, it should be made clear that whilst an off-island placement counts towards the person's eligibility for the period of being 'ordinarily resident' the person must be physically present in Jersey for the request, assessment, approval and provision of the assisted death, which may not be possible in all circumstances. [see section 5 assisted dying process overview]
- 73. Also in line with the Long-Term Care (Residency Conditions) (Jersey) Regulations 2013, for the purpose of the assisted dying law, a person detained under a sentence of imprisonment, youth detention or similar punishment (whether in Jersey or elsewhere) will not be treated as ordinarily resident in Jersey during the period the person is detained. And that the period during which a person is ordinarily resident in Jersey immediately prior detention is treated as if it immediately preceded the person's release from detention.

<sup>&</sup>lt;sup>22</sup> <u>P Resident and Non resident Charging Policy 20140829 MM.pdf (gov.je)</u>

<sup>&</sup>lt;sup>23</sup> <u>r.42-2018.pdf (gov.je)</u>, see pages 13 and 15

74. The circumstances set out in the two paragraphs above are also explicitly included in Regulations under Long-Term Care (Residency Conditions) (Jersey) Regulations 2013, law drafting officers are asked to consider whether the assisted dying law should explicitly provide for these circumstances in the law or whether they are an implicit feature of ordinarily resident in Jersey law. <sup>24</sup>

## Assessing the residency eligibility criteria

- 75. The law will set out that the Coordinating Doctor must be satisfied, before they sign the First Assessment Report Form, that the person is ordinarily resident in Jersey, and has been for a period of 12 months or more at the time of making their First Formal Request.
- 76. There is no requirement for the Independent Assessment Doctor to re-assess the person's residency during the Independent Assessment. The Coordinating Doctor's determination that the person meets the residency criteria is presumed to stand.
- 77. A person cannot request a second opinion assessment on the matter of residency.
- 78. Where the Coordinating Doctor is not satisfied, they cannot find the person eligible. This includes where the person has refused to provide the Information Sharing Consent required to check residency.
- 79. If the person contests they are residentially qualified, despite the determination of the Coordinating Doctor, the person can appeal (see section on appeals in drafting instructions to follow).
- 80. The Coordinating Doctor will generally be satisfied as to residency on the basis that the relevant HCS team has confirmed residency (see below) but confirmation by the relevant HCS team is not requirement of law. The Coordinating Doctor may be satisfied if, for example, they have been the person's GP for a least 12 months, or they can readily see from the person's HCS patient record that the person has been a patient of HCS for more than 12 months. It is important in cases of imminent death (i.e., 14 days or less) that the Coordinating Doctor does not need to rely on confirmation from the HCS team.
- 81. The law will provide that where the Coordinating Doctor requires residency to be checked, person must be asked to provide the relevant Information Sharing Consent as part of the first formal request process (if the Consents have not already been provided).
- 82. The Assessment Guidance will set out that residency checks will generally be undertaken by the HCS team that currently deals with eligibility matters for accessing other HCS services. In order to undertake these checks, the HCS Team

<sup>&</sup>lt;sup>24</sup> Long-Term Care (Residency Conditions) (Jersey) Regulations 2013 (jerseylaw.je), see Article 2 and 3

may need to request information from the person (via the Care Navigator) or from other Government Departments.

- 83. The person will need to provide the relevant Information Sharing Consent as part of the First Formal Request process (if they did not provide at an early stage to the Care Navigator) The Care Navigator will advise the HCS team as soon as the person has provided the necessary Information Sharing Consents. Residency checks will generally be made prior to commencement of the First Assessment process but may, in more complex cases, continue throughout the First Assessment process.
- 84. Where a person contests that they meet the residency criteria despite being initially assessed as not meeting those criteria, the HCS team will generally undertake further proof of residency checks in order to avoid unnecessary appeal to the Royal Court.

## Nature of wish criteria

- 85. The person's wish for assisted dying must be:
  - a. voluntary the assessing doctor must be satisfied that the person is making the request voluntarily i.e., free from any coercion or pressure by another person
  - b. clear and settled the person must be able to clearly articulate their wish for assisted dying and must demonstrate a consistent wish for assisted dying throughout the assessment, approval and provision of an assisted death.
  - c. informed as part of the assessment process the person must be informed by the assessing doctor both about the assisted dying process, their prognosis and any other care and treatment options available to them.

## Assessing the nature of the wish

## Voluntary

- 86. The law will provide that the Assessing Doctor must be satisfied that person's wish to end their own life is voluntary (i.e., that there is an absence of pressure or coercion from any other person to end their life).
- 87. Assessing Doctor includes:
  - a. the Coordinating Doctor before they sign the First Assessment Report Form
  - b. the Independent Assessment Doctor before they sign the Independent Assessment Report Form
  - c. the Second Opinion Doctor (if relevant) before they sign the Second Opinion Assessment Report form

- 88. The law will provide that, in order to satisfy themselves at the voluntary nature of the wish the Assessing Doctor:
  - a. must speak with the person about their reasons for wanting an assisted death, including asking if another person has forced or asked them to request an assisted or they have felt intimated or pressured to request an assisted death
  - b. must seek opinions from connected persons and / or must seek professional supporting assessments and opinions if the Assessing Doctor deems to do so in order to satisfy themselves that the person's wish is voluntary. It is for the Assessing Doctor to determine who the appropriate persons and / or professionals are.
  - 89. The appropriate information sharing consents must be in place (See section on *information sharing consents*)
  - 90. For the purposes of clarity, the law should not compel the Assessing Doctor to seek opinions or assessments if they do not deem it necessary in the circumstances (for example, if the person is in extreme pain, their death is imminent, and the Assessing Doctor is satisfied as to the voluntary nature of the wish based on speaking with the person)
  - 91. The law will provide that the Assessing Doctor cannot determine that the person meets the eligibility criteria if they cannot be satisfied as to the voluntary nature of the wish.
  - 92. The Assessment Guidance will set out that the determination of voluntary nature of the wish may involve discussions:
    - a. with the person's family / friends about how they feel about the person's decision and what they understand to be the person's underlying motivations and wishes, along with observation and assessment of family dynamics. If a person has not provided consent for the Assessing Doctor to speak with family / friends, the Assessing Doctor must inform the person that this may impact their ability to determine that the person is acting voluntarily and without coercion.
    - b. With other professionals providing care and treatment to the person. These professionals may have specific observations or may have had conversations with the person or their carers, family or friends which may provide useful insights into the motivation behind the person's decision. As above, the Assessing Doctor must inform the person that lack of consent to speak with professionals may impact the Assessing Doctor's ability to determine that the person is acting voluntarily and without coercion
- 93. Indicators of possible coercion that may be detected during a consultation with carers, family or friends present could include:

	a. excessive deferment by the person to their carers, family or friends for
	answers, reassurance or explanation
	b. carers, family or friends talking over the person and answering on their behalf
	<ul> <li>inconsistencies in the person's answers to questions about their suffering, illness experience or assisted dying in general</li> </ul>
	d. inconsistencies between what the person says in private to the Assessing Doctor, and what the person says in the presence of others.
94.	For these reasons, it may be necessary to talk with the person away from others to determine if there is potential coercion. Questions the Assessing Doctor could ask in their discussion with the person may include:
	<ul> <li>Are you feeling any pressure from others to request assisted dying?</li> </ul>
	<ul> <li>Do you have or are there any significant financial concerns?</li> </ul>
	<ul> <li>Do you have any concerns about your family after you die?</li> </ul>
	<ul> <li>Is there anything we need to know that you don't want your family to know?</li> </ul>
	<ul> <li>What about your family/friends (may include partners, spouse, children, parents, siblings)?</li> </ul>
	<ul> <li>Are they aware of your request for assisted dying?</li> </ul>
	<ul> <li>How do they feel about it?</li> </ul>
	<ul> <li>Do they support your decision?</li> </ul>
	<ul> <li>Is your GP aware of your request for assisted dying?</li> </ul>
	<ul> <li>Does your GP support it?</li> </ul>
	Further detail for assessing the voluntariness of a person's decision will be provided in the Assessment Guidance.
95.	The Assessment Guidance will set out that if there is a concern that the person may be experiencing family and domestic violence, financial abuse or elder abuse these issues should be discussed with the person. These concerns should also be considered at an MDT meeting. The Guidance will also set out that the Assessing

Doctor must make a referral to the appropriate adult safeguarding team if there are any safeguarding concerns regarding abuse.<sup>25</sup>

Clear and settled wish for assisted dying

- 96. The law will provide that the Assessing Doctor must be satisfied that person's wish to end their own life is clear and settled.
- 97. Assessing Doctor includes:
  - a. the Coordinating Doctor before they sign the First Assessment Report Form
  - b. the Independent Assessment Doctor before they sign the Independent Assessment Report Form
  - c. the Second Opinion Doctor (if relevant) before they sign the Second Opinion Assessment Report form
- 98. The law will provide that, in order to satisfy themselves as to the clear and settled nature of the wish the Assessing Doctor must:
  - a. must speak with the person about their reasons for having an assisted death, including asking how long they have been considering requesting an assisted death and whether their wish for an assisted death is consistent or fluctuates
  - b. must seek opinions from connected persons and / or must seek professional supporting assessments and opinions if the Assessing Doctor deems to do so in order to satisfy themselves that the person's wish is clear and settled. It is for the Assessing Doctor to determine who the appropriate persons and / or professionals are.
- 99. The appropriate information sharing consents must be in place (See section on *information sharing consents*)
- 100. For the purposes of clarity, the law should not compel the Assessing Doctor to seek opinions or assessments if they do not deem it necessary in the circumstances.
- 101. The law will provide that the Assessing Doctor cannot determine that the person meets the eligibility criteria if they cannot be satisfied that the wish is clear and settled.
- 102. Note: The 14-day minimum timeframe provided for in the law, with the exception of those with a less than 14-days life expectancy (*See section on minimum timeframes*) allows a period of time for the assessing doctors to determine that the person is throughout that 14-day period consistent and settled in their wish for an assisted death.

<sup>&</sup>lt;sup>25</sup> <u>Report A Concern | Jersey Safeguarding Partnership Board</u>

- 103. Assessment Guidance will set out that in order to determine that the person's wish is clear and settled, the Assessing Doctor must discuss with the person their reasons for requesting an assisted death.
- 104. The first assessment process must fully explore with the person their request for an assisted death and the fears, anxieties and suffering that gives rise to that request as well as their understanding of the impact of requesting and having an assisted death.
- 105. The Assessing Doctor must also consider any previous assisted dying requests and or withdrawal of requests.
- 106. The purpose of these discussions is for the Assessing Doctor to understand the person's wishes and why the person thinks accessing assisted dying will address any concerns. The Assessing Doctor will ask the person how they reached their decision, including what or who may have influenced them.
- 107. If a person is requesting access to assisted dying because they are concerned that they are a burden on their carers or family, their situation should be explored. This may include the Assessing Doctor requesting that another member of the MDT, for example the social worker, reviews with the person their current care package and explores additional options for supportive care or respite care.
- 108. The Assessing Doctor should also seek to understand why the person has raised this concern and what they mean by it. Some people may say they feel like they are a burden because they believe or know that their family members are struggling to support them at the end of their life, while others may use this to start a discussion about their struggles with their current situation such as their sense of burden or loss of dignity. Such comments should also raise a 'red flag' to the Assessing Doctor to explore whether there may be any element of explicit or implicit coercion underlying the person's request for assisted dying.
- 109. Further detail for assessing the clear and settled nature of a person's decision will be provided in the Assessment Guidance.

Informed wish for assisted dying

- 110. The law will provide that the Coordinating Doctor must do the following to help ensure that the person's wish is informed:
  - a. they must inform the person of the matters set out below which are pertinent to the individual circumstances of the person / or make arrangements for another suitability qualified person to inform the person of those matters and confirm that the person has been so informed, AND
  - b. provide to the person the *Approved Information* which sets out general matters related to the assisted dying process (see section on Step 1 first formal

request), and satisfy themselves that the person understands that information (with or without communication support)

- 111. The Coordinating Doctor must do this before they sign the First Assessment Report Form
- 112. The Independent Assessment Doctor must:
  - a. also inform the person of the matters set out below which are pertinent to the individual circumstances of the person / or make arrangements for another suitability qualified person to inform the person of those matters and confirm that the person has been so informed, AND
  - b. confirm that the person has been provided the *Approved Information* which sets out general matters related to the assisted dying process (see section on Step 1 first formal request) and satisfy themselves that the person understood that information (with or without communication support).
- 113. The Independent Assessment Doctor must do this before they sign the Independent Assessment Report Form
- 114. A Second Opinion Doctor must, if they are assessing matters relating to the nature of the wish:
  - a. confirm the person has been informed of the matters set out below which are pertinent to the individual circumstances of the person / or inform the person of those matters / or make arrangements for another suitability qualified person to inform the person of those matters and confirm that the person has been so informed, AND
  - confirm that the person has been provided the *Approved Information* which sets out general matters related to the assisted dying process (see section on Step 1 – first formal request) and be satisfied that the person understood that information (with or without communications support)
- 115. A Second Opinion Doctor must do this before they sign the Second Opinion Assessment Report form
- 116. The matters that are pertinent to the individual circumstances of the person are:
  - a. information about the patient's diagnosis and prognosis
  - b. information about the care and treatment options available to the person and likely outcome of those care and treatment options including:
    - palliative and end of life care and treatment options and the likely outcomes
    - care and treatment options that the person may previously have discounted or discontinued.
    - c. options for the methods for person to self-administer the substance or have the assisted dying substance administered including:

- the modes of delivery associated with those options (e.g. oral ingestion, or intravenous administration)
- appropriateness of the options and methods for the person
- d. the potential risks associated with the option and methods and modes of delivery that are available to the person

(Note: whilst Approved Information includes general matters relating to the administration / self-administration of the assisted dying substance, the Assessing Doctor must inform the person about how this applies to them in their circumstances (for example, they may not have a swallow function which would prevent oral ingestion)

- e. information about locations for the person's assisted death
- f. information about the involvement of family / friends in the delivery of the assisted death, and associated risks
- g. information about:
  - the provision of confirmation of consent to proceed (including implications of doing so / not doing so) and / or
  - making a declaration of waiver of final confirmation of consent (including implications of doing so / not doing so) and / or
  - making an advanced decision/s to refuse treatment (ADRT), for example refusing resuscitation or similar emergency life-saving interventions (including implications of doing so / not doing so)<sup>26</sup>.
- 117. The Assessing Doctor must also:
  - a. Inform the person that the expected outcome of self-administering or being administered the assisted dying substance is death
  - b. Inform the person that they:
    - may withdraw their request at any point during the process
    - must confirm their wish to proceed at each step and may choose not to proceed to any of the steps
  - c. inform them of the appeals process
  - d. encourage the person to talk to their family / friends about their request unless the Coordinating Doctor, having discussed the matter with the person, is not of the opinion that there are reasonable circumstances for them not to do so. For example, if the person is in an abusive relationship.
  - e. support the person to determine whether they want other attending practitioners and carers to be informed of their wishes, if they have not already done so.
- 118. The Assessing Doctor must be satisfied that the person has understood the information discussed during the assessment. As described in the Section on *Communication Support*, the Assessing Doctor has duty to consider and make arrangements for the appropriate level of communications support.

<sup>&</sup>lt;sup>26</sup> ID Making an Advance Decision to Refuse Treatment (ADRT) -Guidance Notes.pdf (gov.je)

- 119. The law will provide that the Assessing Doctor cannot determine that the person meets the eligibility criteria if they cannot be satisfied the person's decision is informed.
- 120. The Assessment Guidance will provide that, in informing the person about the care and treatment options available to them (and the likely outcome of those care and treatment options), this must include information about counselling services, mental health and disability support services, community services, in addition to hospice and palliative care services. Furthermore, the Assessing Doctor must offer to arrange consultations with the professionals providing such services or care that may be available to the person.

### Decision-making capacity criteria

- 121. The law will state that a person is only eligible for assisted dying if they have capacity to make an assisted dying decision.
- 122. An assisted dying decision includes:
  - a. a decision to make an <u>informed request</u> for an assisted death. An informed request is made when the person makes their second formal request at the end of Step 4 (For clarity, when the person makes their first formal request, it is by nature, not yet informed as the person has not undertaken the assessment process)
  - b. a decision to <u>proceed to the next step in the assisted dying process</u>. A decision to progress is made when the person signs the Step Transition Form at the:
    - end of Step 2 (the person is deciding to proceed to have an Independent Assessment)
    - end of Step 3 (the person is deciding to proceed to considering making a second formal request)
  - c. a decision to <u>agree arrangements</u> for their assisted death. Arrangements for an assisted death are agreed during Step 6 assisted death care planning
  - d. a <u>decision to have an assisted death</u>. A decision to have an assisted death is made:
    - when the person signs the final Step Transition Form at end of the Administrative Review process (end of Step 5)
    - when final consent is given by the person, with the person's capacity to make the decision being assessed during the Final Review (during Step 7)

123. The requirement for decision-making capacity is present in other jurisdictions including New Zealand (*"is competent to make an informed decision about assisted dying"*<sup>27</sup>), California (*"Capacity to make medical decisions"*<sup>28</sup>). A specific test for decision-making capacity in relation to assisted dying is set out in Australian jurisdictions, all with broadly similar phrasing.<sup>293031</sup>:<sup>3233</sup>

## Capacity to make a decision

- 124. The Capacity and Self-Determination (Jersey) Law 2016 ('the 2016 law') provides a legal framework for making 'best interest' decisions on behalf of people who lack the capacity to make a decision for themselves (for example, where a person does not have capacity to consent to life-saving treatment another appropriate person may consent to treatment on their behalf)..<sup>34</sup>
- 125. The underlying reason for determining capacity in relation to an assisted dying decision is different to the underlying reason for determining capacity in the 2016 law:
  - in the assisted dying law, it must be determined that the person <u>has capacity</u> to make an assisted dying decision. If they do not have capacity, they cannot be found eligible for an assisted dying and no other person may make an assisted dying decision on their behalf
  - in the 2016 law when it is determined that a person *does not have capacity* to make a decision, a 'best interests' decision can be made on their behalf.

## Presumption of capacity

- 126. Article 3 of the 2016 law sets out the principle that *a person must be assumed to have capacity unless it is shown that the person lacks capacity.* This is an important principle as it ensures proper respect for personal autonomy, and it requires any decision that the person lacks of capacity to be based on evidence.
- 127. The assisted dying law should set out the same principle i.e., a *person must be assumed to have capacity (to make an assisted dying decision) unless it is shown that the person lacks capacity.* Presumption of capacity is a feature of assisted dying

<sup>&</sup>lt;sup>27</sup> End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 5 Meaning of person who is eligible for assisted dying or eligible person – New Zealand Legislation

<sup>&</sup>lt;sup>28</sup> Bill Text - SB-380 End of life. (ca.gov)

<sup>&</sup>lt;sup>29</sup> Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au) – See Article 4

<sup>&</sup>lt;sup>30</sup> Voluntary Assisted Dying Act 2022 No 17 - NSW Legislation

<sup>&</sup>lt;sup>31</sup> Voluntary Assisted Dying Act 2019 - [00-00-00].pdf (legislation.wa.gov.au) - See Article 6

<sup>&</sup>lt;sup>32</sup> Voluntary Assisted Dying Bill 2021 (legislation.qld.gov.au) – See Article 11

<sup>&</sup>lt;sup>33</sup> <u>Voluntary Assisted Dying Act 2021 (legislation.sa.gov.au)</u> – See Article 4

<sup>&</sup>lt;sup>34</sup> Capacity and Self-Determination (Jersey) Law 2016 (jerseylaw.je)

laws in other jurisdictions (for example in New South Wales and Western Australia, and in Queensland, South Australia and Tasmania albeit it these jurisdictions it is phrased as a presumption of capacity *unless there is evidence to the contrary*).

128. Whilst the law will set out a presumption of capacity, that presumption alone cannot be relied on by an assessing doctor / administering practitioner who must, by law, be <u>satisfied that the person has the capacity to make an assisted dying decision</u>. The assessing doctor / administering practitioner cannot use the presumption to avoid taking responsibility for satisfying themselves that the person has the capacity to make an assisted dying decision (as described below) when there is concern that they may not have capacity.

Capacity to make an assisted dying decision (capacity "test")

- 129. A person has capacity to make an assisted dying decision if they have the capacity to:
  - a. understand any information or advice about an assisted dying decision that is required under the law to be provided to them
  - b. understand the matters involved in an assisted dying decision
  - c. understand the effect of an assisted dying decision
  - d. weigh up the factors referred to above for the purposes of making an assisted dying decision
  - e. retain that information to the extent necessary to make the decision
  - f. communicate an assisted dying decision in some way (including verbally, using gestures or by other means).
- 130. A person has capacity to make an assisted dying decision, even where the person requires additional practicable and appropriate support to make that decision.
- 131. Examples of practicable and appropriate support include (but are not limited to):
  - giving information to and receiving information from a person in a way that is tailored to their needs
  - communicating, or assisting a person to communicate, the person's decision, for example, with the assistance of an interpreter or communication support
  - giving a person additional time when discussing the matter with the person

- using technology that alleviates the effects of a person's disability (for example, text-to-speech software could be used by a person who is unable to speak)
- 132. A The law must provide that:
  - a. if a person requires practicable and appropriate support to make an assisted dying decision, that support must be provided
  - anyone providing practical and appropriate support must not use excessive persuasion or undue pressure. This might include behaving in a manner which is overbearing or dominating or seeking to influence the person to make a decision they might not otherwise have made. (A similar provision is used in the assisted dying laws in Australia for example, Victoria<sup>35</sup> and Queensland.<sup>36</sup>)

### NOTE: Capacity to make a decision / Capacity to make an assisted dying decision

A person who has made an assisted dying request may, in relation to the request, make both assisted dying decisions (as described in paragraph 122 above) and 'non-assisted dying decisions', for example:

### Capacity law decision

A person has made an assisted dying request. Their Coordinating Doctor has requested a supporting assessment (a lung function capacity test) to support their determination whether the person is eligible for an assisted death. The person arrives at the clinic but, before the test has begun, the respiratory nurse has reason to believe the person may lacks capacity to consent to the test. The nurse then assesses the person's capacity, in accordance with the 2016 law and code of practice, as opposed assisted dying because the person is not making an assisted dying decision, they are only required to give consent to having the lung function test which is provided for under the 2016 law.

In the event the nurse concludes the person does not have the capacity to consent to a lung function test, they would inform the Coordinating Doctor who must then determine whether they are satisfied that person has capacity to make an assisted dying decision.

### Assisted dying law capacity decision

During a First Assessment the Coordinating Doctor determines a person does has capacity to make an assisted dying decision to request to proceed to the next step of the process. During the Independent Assessment, the person presents as confused and disorientated and the Independent Assessment Doctor, having assessed their capacity cannot be satisfied that the person has capacity to make an assisted dying decision and assesses the person as ineligible.

<sup>&</sup>lt;sup>35</sup> <u>Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au)</u> – see article 4 (4) (d)

<sup>&</sup>lt;sup>36</sup> Voluntary Assisted Dying Bill 2021 (legislation.qld.gov.au) – see article 11 (3) (d)

Both the Coordinating Doctor and the Independent Assessment Doctor made decision that related to the person ability to make an assisted dying decision under the assisted dying law.

### Assessing the decision-making capacity criteria

- 133. The law will need to set out an assumption of capacity to make an assisted dying decision, but also provide that the Assessing Doctor / Administering Practitioner must be satisfied that the person has capacity to make an assisted dying decision)
- 134. The law will provide that, where:
  - a. the Assessing Doctor is not satisfied that the person has capacity to make an assisted dying decision, they cannot determine that the person meets the eligibility criteria – which will result in request refusal
  - b. the Administering Practitioner is not satisfied that the person has capacity to make an assisted dying decision:
  - during Step 6, the person cannot proceed to Step 7, or
  - during Step 7, the person cannot have an assisted death unless a Waiver of Final Confirmation of Consent is in place
- 135. Assessment Guidance will set out that the Assessing Doctor / Administering Practitioner may have doubts about the person's capacity based on their interactions with the person, the person's medical history and / or information provided to them by third parties.
- 136. The law will provide that the Assessing Doctor/Administering Practitioner cannot rely on the presumption of capacity alone to avoid taking responsibility for satisfying themselves that the person has the capacity to make an assisted dying decision. Where they have doubts as to the person's capacity, they must – in order to satisfying themselves as to the person's capacity:
  - a. assess the person's capacity to make an assisted dying decision, if they have the necessary expertise or training to do so OR
  - seek supporting assessments / opinions from a relevant professional (i.e., a professional whom they determine has the necessary expertise and training to make such a determination). This may be a relevant professional who was previously involving in assessing the person's capacity

Having undertaken an assessment (or having received and reviewed the professional opinions or assessments) the Assessing Doctor / Administering Practitioner must determine if they are now satisfied that the person has capacity to make an assisted death decision. If they are not satisfied, they cannot proceed.

- 137. The law will set out that the Assessing Doctor / Administering Practitioner and / or any other relevant professional who is assessing whether a person has decision-making capacity must take reasonable steps to conduct the assessment at a time and in an environment in which the person's decision-making capacity can be most accurately assessed, with support if required. This provision is provided for in the South Australia assisted dying law.<sup>37</sup>
- 138. The following forms must include the Assessing doctor's/ Administering Practitioner's confirmation that they are satisfied as to matters of capacity:
  - a. All step transition forms
  - b. All information sharing consents forms
  - c. First Assessment Report Form
  - d. Second Opinion Assessment Report form
  - e. Independent Assessment Report form
  - f. Second Formal Request Form
  - g. Assisted Death Care Plan form
  - h. Final Consent and Review form.

### 139. The Assessment Guidance will set out that:

- a. The Assessment Guidance will provide that depending on the person's medical condition and any comorbid mental illness, relevant professionals to undertake a capacity assessment may include a psychiatrist, geriatrician, psychologist or specialist social worker.
- b. Capacity is time and decision-specific. This means the Coordinating Doctor should assess a person's ability to make a specific decision at the time the decision needs to be made. Therefore, during the first assessment the person must demonstrate they want to make a request for assisted dying and proceed through the assisted dying process. At the point of delivery, prior to the administration of the substance [Step 7] the person must have decisionmaking capacity to make the decision to want to proceed with administration of the substance, with the capacity to understand it is going to result in their immediate death.
- c. Some people may have fluctuating capacity, this means they may lack capacity to make a specific decision at one point in time but may have capacity to make the same decision at a different point in time. The Assessing Doctor / Administering Practitioner must be satisfied that there is no evidence that the person lacks capacity at the point at which an assisted dying decision is made but, between those decision-making points, it is accepted the person may not have capacity.

<sup>&</sup>lt;sup>37</sup> <u>Voluntary Assisted Dying Act 2021 (legislation.sa.gov.au)</u> – see article 4 (5)

d. Where a person who has known fluctuating capacity and does not have capacity to make a decision at the point in time at which it is envisaged that the decision will be taken, the Assessing Doctor / Administering Practitioner may decide to delay decision-making until a point in time when the Assessing Doctor / Administering Practitioner determines the person has capacity. This is because it must be recognised that the drugs used to manage pain may have a temporary / fluctuating impact on decision making capacity.

### Application of eligibility criteria

- 140. The age and residency criteria apply at the point in time at which a person makes a first formal request for assisted dying.
- 141. All other eligibility criteria must apply at the point in time when an assessment is completed (first assessment, independent assessment or any second opinion assessment)
- 142. If the person does not meet all the eligibility criteria, when assessed, they cannot proceed through the rest of the assisted dying process, but they may start the process again should there be changes in their circumstances -see section on *Repeat first requests*.

### Future changes to eligibility criteria

- 143. Any future changes to eligibility criteria will require amendments to the primary law, the law will not provide a Regulation making power for this purpose. This safeguard is intended to ensure that Privy Council, as well as the States Assembly, are sighted on any changes and to provide a counter to the 'slippery slope' concerns around the expansion of eligibility criteria raised by some in consultation feedback.
- 144. For the purposes of clarity, no person may have an assisted death in Jersey unless they have request approval; request approval can only be provided by the Coordinating Doctor; the Coordinating Doctor can only provide request approval if the Coordinating Doctor has determined that the person meets all the eligibility criteria in law; the Coordinating Doctor cannot determine that the person meets all the eligibility criteria unless the Coordinating Doctor is satisfied that the assisted dying process has been undertaken in accordance with the law.

## 3. Jersey Assisted Dying Service

This section outlines the establishment of a Jersey Assisted Dying Service. It also sets out how the Jersey Assisted Dying Service will operate, including the governance structures.

### Establishing the Jersey Assisted Dying Service in law

- 145. The law will set out that the Health and Social Services Minister ("the Minister") must make arrangements to establish and maintain an assisted dying service in Jersey (the "Jersey Assisted Dying Service")
- 146. For the purposes of safeguarding people, the law will provide that no other person or entity other than the Jersey Assisted Dying Service can:
  - a. provide an assisted dying service in Jersey
  - b. purport to provide an assisted dying service in Jersey
  - c. refer to itself, or cause or permit another person to refer to it as the Jersey Assisted Dying Service (see Offences in law drafting instructions to follow)
  - d. can advertise or promote the Jersey Assisted Dying Service.
- 147. The law will provide that no person or entity can charge for provision of an assisted dying service in Jersey, including the Minister. This includes charging for the assisted dying assessment process and / or the delivery of an assisted death regardless of the assessment and/ or delivery location (for example whether in an HCS facility, the person's home or in another location)
- 148. However, the law should provide that the Assembly may determine by Regulations that the Minister, or provider of the Assisted Dying Service in the event that it is not the Minister, may levy a fee to access the Jersey Assisted Dying Service, but may only do so in the event that Assembly is satisfied that this is consistent with the approach to other healthcare services provided by the Minister at that time- i.e. in the event where service user charges are introduced, as standard, for Government delivered health and care services.
- 149. The law will provide that the Jersey Assisted Dying Service will be managed and delivered by a Department of Government unless Assembly determines that the Jersey Assisted Dying Service should be provided by a different person or entity. See *Change of Provider Regulations* below.
- 150. As per the proposals adopted by the Assembly, the Health and Community Services Department ("HCS") will manage and deliver the Assisted Dying Service.

**NOTE:** The approach of a separate assisted dying service is supported by the British Medical Association (BMA), who states:

The way in which any future assisted dying service would be delivered in practice would have a very significant impact on doctors. For that reason, if the law were to change, the BMA would want to see:

### Assisted dying to be arranged through a separate service

The BMA does not believe that assisted dying should be integrated into existing care pathways (whereby a patient's GP, oncologist or palliative care doctor would, at the patient's request, provide assisted dying as part of the standard care and treatment they provide). In the BMA's view, assisted dying should be arranged, but not necessarily delivered, through a separate service that would accept referrals from other professionals and/or self-referrals. (This does not necessarily mean separate from the NHS.) Doctors who wanted to do so could still assist their own patients, but this would be arranged, and potentially managed, through a different pathway. The model proposed in Jersey, whereby the Jersey Assisted Dying Service would 'coordinate and deploy the professionals' who would provide the service, provides an example of how this could work. In our view, this would be better for doctors and for patients and would help to ensure consistency, and facilitate oversight, research and audit of the service.<sup>38</sup>

### Change of provider regulations

- 151. Notwithstanding the intention that the service is delivered by HCS, the law should not preclude the Minister from making arrangements for a different entity to provide the Jersey Assisted Dying Service if, as some point in the future, the Minister were to be satisfied that another entity was better placed to manage and deliver the service, and that the entity would do so in accordance with the law [and see paragraph 157].
- 152. The law must, therefore, provide that the Assembly may determine by Regulations that the Assisted Dying Service should be provided by a different entity other than HCS, in the event the Assembly is satisfied that:
  - a. the person / entity can provide an effective, efficient assisted dying service which accords with all the requirements of the law
  - b. the Minister has consulted with such persons or bodies as appear to the Minister to be representative of persons who would be affected by a change of providers (for example, consulted the UK professional regulatory bodies)
- 153. The Regulations will also need to provide that the Assembly:
  - a. may make all appropriate transfer arrangements necessitated by the change of providers (for example, the arrangements necessary to transfer staff, equipment,

<sup>&</sup>lt;sup>38</sup> Physician assisted dying (bma.org.uk)

facilities, information and records - including individual's assisted dying patient records - and the care of patients from the existing provider to the new provider as necessary)

- b. may create offences and prescribed penalties if the Assembly deems it necessary as a result of change of provider
- c. may make amendments to any other provisions of the assisted dying law that are necessitated by the change of provider, for example, the governance and oversight arrangements associated with the Service (for example the establishment and functions of Assisted Dying Assurance and Delivery Committee)
- d. may make consequential amendments to other laws as required (for example, amendments to the Regulation of Care Law if necessitated by the change of provider
- e. may not provide for changes to the assisted dying eligibility criteria
- 154. For the purposes of clarity, the Assembly may determine to make Change of Provider Regulations at any point, and on as many occasions as the Assembly determine is necessary.
- 155. In placing a duty on the Minister to make arrangements to establish and maintain an assisted dying service, it must be recognised that there may be circumstances in which the Minister cannot make the necessary arrangements. For example, if the assisted dying service cannot be appropriately and safely staffed because professionals do not wish to work in the service.
- 156. The law should therefore provide that if it appears to Minister that the Minister is unable to establish and / or maintain an Assisted Dying Service that accords with the law, the Minister must lay before the Assembly a report setting out:
  - a. why it appears to the Minister that they are unable to establish and / or maintain an Assisted Dying Service (i.e., grounds for not establishing / maintaining the service)
  - b. any associated actions, if any, the Minister intends to take
  - c. details of any actions taken to address the factors the prevent or inhibit the establishment / maintenance of the Assisted Dying Service
  - d. what decisions, if any, the Minister recommends the Assembly takes in order to enable the Minister to establish and / or maintain an Assisted Dying Service
- 157. Before laying such a report before the Minister must consult with such persons or bodies as appear to the Minister to be representative of persons who would be

affected by a change of providers (for example, the Jersey Assisted Dying Service, UK professional regulatory bodies)

- 158. The ground for not establishing / maintaining the Service must relate to safe service provision, they cannot relate to other matters including matters of the Minster's conscience.
- 159. In the event that the Assembly determines that they agree that the Minister is unable to establish and / or maintain an Assisted Dying Service that accords with the law, the law should provide that the Minister is not in dereliction of duty by not establishing or maintaining that service.

### Functions of the Jersey Assisted Dying Service

- 160. The law will set out the functions of the Jersey Assisted Dying Service. These functions include a requirement to:
  - a. develop and publish information about assisted dying in Jersey both online and in printed formats, including the provision of accessible information (information which is able to be read or received and understood by the individual or group for which it is intended) and alternative formats (for example, large print versions for those with visual impairments) <sup>39</sup> This will include:
    - information on the assisted dying service and the assisted dying process, including the service's contact details - in a format that is appropriate for health and care professionals to provide to the patients, should the patient raise the matter of assisted dying and the health and care professional exercises their right to refuse to participate
    - any non-professional guidance or professional guidance that the Committee deems should be made available to the public
  - b. provide information about assisted dying in Jersey to any person requesting it, in response to queries from the public and professionals
  - c. provide the assisted dying service which includes:
    - coordination and delivery of the assisted dying process
    - undertaking all administrative, management and governance tasks associated with delivery of the assisted dying process, including those required by law or as directed by the Assurance and Delivery Committee
  - d. provide or make arrangements for the provision of wellbeing support (e.g.: counselling) and information to persons requesting an assisted death / people with special interest in the care and treatment of a person who have requested

<sup>&</sup>lt;sup>39</sup> <u>NHS England Report Template 1 - long length title</u> – see NHS Accessible Information Standard specification for detailed description of accessible information and alternative formats

an assisted death or had an assisted death (for example, family members) / assisted dying practitioners.

- e. maintain the assisted dying practitioner register on behalf of the Assisted Dying Assurance and Delivery Committee and in accordance with any requirements of Committee or the law, or Order of the Minister
- f. engage, coordinate and deploy the assisted dying practitioners and the Care Navigators who will support delivery of the assisted dying process
- g. hold all assisted dying records and forms in accordance with Committee's retention schedule and retention arrangements and as required to do so by the law, or Order of the Minister
- h. arrange interpretation, communication or advocacy support for persons who have requested an assisted death in accordance with the provisions of the law.
- 161. The Jersey Assisted Dying Service will only provide assisted death assessments to persons who are eligible to access free non-emergency hospital care in accordance with the Minister's published access criteria (the access criteria for free non-emergency hospital care are set out in the HCS Residents and Non-Residents Charging policy)<sup>40</sup> and will only provide assisted death delivery services (Steps 6 to 8 in the assisted dying process) to persons who, in addition to meeting the assisted dying criteria, are also eligible to access free non-emergency hospital care in accordance with the Minister's published access criteria (the access criteria for free non-emergency hospital care in accordance with the Minister's published access criteria (the access criteria for free non-emergency hospital care are set out in the HCS Residents and Non-Residents Charging policy).
- 162. The Minister's access criteria for free non-emergency care may be subject to change, so access will be in accordance with the published criteria at the point at which the person makes their first formal request for an assisted death.
- 163. For the avoidance of doubt, where a person is:
  - a. not entitled to access free non-emergency hospital care in accordance with the Minister's published criteria, the person will not be able to access the Assisted Dying Service (except for the purpose of requesting information), this includes not being able to access it as a paid-for service as per other HCS non-emergency hospital services on the basis that the law will prohibit assisted dying being provided as a paid-for service
  - b. is entitled to access free non-emergency hospital care in accordance with the Minister's criteria, this does not entitle the person to an assisted death.

<sup>&</sup>lt;sup>40</sup> <u>P Resident and Non resident Charging Policy 20140829 MM.pdf (gov.je)</u>

### Assisted Dying Assurance and Delivery Committee (and its functions)

- 164. The law will provide that an *Assisted Dying Assurance and Delivery Committee* ("the Committee") must be established by the Minister.
- 165. The primary function of the Committee is to ensure that the Jersey Assisted Dying Service operates in accordance with the law
- 166. Other functions of the Committee must include:

### matters related to the establishment of the Jersey Assisted Dying Service, including:

- a. making arrangements for the development of the following, and approving and publishing the following:
  - information about the Jersey Assisted Dying Service. This information should be both online and in printed formats and include accessible information (i.e. information which can be read or received and understood by the individual or group for which it is intended) and alternative formats (for example, large print versions for those with visual impairments) <sup>41</sup>
  - Jersey Assisted Dying Service service standards (for example, target maximum timeframes for the Service to undertake the assisted dying process or to respond to poor service complaints)
  - the retention schedule and retention arrangements for all records held by the Jersey Assisted Dying Service
  - non-professional guidance.
- b. making arrangements for the development of the following, approving the following and making available to relevant persons:
  - the assisted dying training programme (see section on *Competency frameworks, training and qualifications*)
  - the assisted dying refresher training programme
  - an Appropriate Conversations training programme
  - professional guidance required under the law
  - competency frameworks for all assisted dying practitioners and ADRMP

<sup>&</sup>lt;sup>41</sup> <u>NHS England Report Template 1 - long length title</u> – see NHS Accessible Information Standard specification for detailed description of accessible information and alternative formats

- the Assisted Dying Person Record system (see section on *Assisted Dying Person Record and Guidance*)
- processes and standards for investigation and response to safety concerns, complaints relating to service standards, and whistleblowing to be made available to the public the process for making complaints against service standards, raising safety concerns and whistleblowing procedures
- the Assisted Dying Declaration of Interests Policy (see section on *Registration Declaration and Specific Person Declaration*)

**Note – relevant persons:** The Committee must determine who the relevant persons are. This may be all persons (i.e., the public) or specific groups of people (for example, assisted dying practitioners). In making their determination the Committee must consider the potential for the information to be used by people with ill intent (for example, will publication of detailed information about the assessment process support people to manipulate that process?). The law will provide that the Committee:

- may make available some of the information, or all of the information to different people (i.e., some sections of the competency framework may be publicly available, others may not)
- may make available in the form the Committee deems appropriate (i.e., online, paper copies)
- must consult the Minister when determining the relevant persons.
- c. making arrangements for the development and publication of all forms related to the assisted dying process, having consulted on the development of the forms with any entity the Committee or the Minister deems relevant.
- d. making arrangements to establish the register of assisted dying practitioners and ensuing maintenance of that register by the Jersey Assisted Dying Service (see section *Registration as an assisted dying practitioner*)
- e. making arrangements for the development and provision of systems that support involved professionals and Care Navigators (i.e., those who are directly involved in the assisted death) to process and reflect on the impact and emotions associated with assisting a person to die (for example, counselling / therapeutic de-briefing; peer support groups)
- f. making arrangements for the development of the authorised drug regimen, and then approve the regimen. In doing so the Committee must consult any organisation or body that the Committee deems relevant. This may include, for example
  - Chief Pharmacist
  - the General Pharmaceutical Council
  - the Royal Pharmaceutical Society

the Medicines and Healthcare Products Regulatory Agency

The drugs regimen will not be published due to the sensitivity of the information set out in that regimen (see Section *on Prescribing, preparing and dispensing the assisted dying substance* for more information about the authorised drugs).

g. any other matters relevant to the establishment of the Jersey Assisted Dying Service as directed by the Minister

### oversight of the Jersey Assisted Dying Service, including:

- h. establishing systems to compile data and monitor the following matters related to service safety, service quality and service usage / uptake and to undertake that monitoring:
  - compliance with the assisted dying law
  - compliance with the professional guidance
  - management and response to complaints
  - investigation and response to patient safety concerns or incidents or service risks
  - compliance with the Jersey Assisted Dying Services service standards
  - data related to outcomes and numbers and profile of service users (see section on Annual report below)
- i. providing assurance to the Minister and the public about patient experience, clinical safety and service quality
- j. producing an annual report on assisted dying in Jersey for presentation to Minister (see section on *Annual report on assisted dying in Jersey* below)
- k. establishment of an Assisted Dying Review Panel, including making arrangements for the recruitment of Panel members to be appointed by the Minister (see section on *Post-death review*)
- I. making arrangements for the development or subsequent amendment of the Assisted Dying Review Panel's terms of reference, to be adopted by a decision of the Minister. Prior to presenting those terms of reference to the Minister, the Committee must consult the Jersey Care Commission and any other entities or persons that the Committee deems are relevant to consult (see section 8, Regulation and oversight).
- m. commissioning request reviews reports from the Assisted Dying Review Panel, receiving post-death review reports, process review reports and request review reports from the Assisted Dying Review Panel. Giving due consideration to the Panel's determination, findings and recommendations, determining the action to be taken

n. any other matters relevant to the ongoing monitoring and oversight of the Jersey Assisted Dying Service, as directed by the Minister

# Development of Professional Guidance, other core documents and non-professional guidance

- 167. In addition to the Professional Guidance that is provided for in Law, the Committee may, with the approval of the Minister, make arrangements to develop of other Professional guidance that the Committee considers to be necessary. The Committee must approve any such professional guidance and make available to relevant persons.
- 168. The Committee may amend any Professional Guidance that the Committee has previously approved and published as the Committee deems appropriate.
- 169. In developing or amending the professional guidance the Committee must consult with the entities or persons that the Committee deems are relevant to consult ("relevant consultees"). For example, in developing the prescription and administration guidance, the Committee must consult the following, as these would be deemed relevant consultees by the Committee:
  - Chief Pharmacist
  - the General Pharmaceutical Council
  - the Royal Pharmaceutical Society
  - the Medicines and Healthcare Products Regulatory Agency.
- 170. Similarly, the Committee may amend any of the following as the Committee deems appropriate, but in developing or amending these core documents it must consult relevant consultees:
  - the training programme
  - competency frameworks
  - authorised drug regimen
  - service standards
- 171. In addition to the non-professional guidance that is provided for in Law, the Committee may make arrangements to develop any other non-professional guidance that the Committee considers to be necessary. The Committee does not require approval of the Minster to produce non-professional guidance.
- 172. The Committee must approve and publish non-professional guidance.
- 173. The Committee may amend any non-Professional Guidance that the Committee has previously approved and published as the Committee deems appropriate.
- 174. In developing or amending the non-professional guidance the Committee may consult with the entities or persons that the Committee deems are relevant to consult.
- 175. The law will provide the Committee with powers to:

- a. investigate matters relating to practice of professionals whilst working in the capacity of registered assisted dying practitioners, including the powers to suspend whilst an investigation is underway, or to remove a professional from the assisted dying register after the conclusion of an investigation (see section *Registration as an assisted dying practitioner*). The arrangements relating to the investigation, suspension and removal of professional from the assisted dying register will be provided for by Regulation.
- b. share or disclose information about the practice of any registered assisted dying practitioner whilst working in the capacity of an assisted dying practitioner with any relevant entity, as determined by the Committee (for example, UK professional regulatory bodies, the Jersey Care Commission, the Attorney General and the Viscount), or any other employer of the assisted dying practitioner, if:
  - the information has previously been lawfully disclosed to the public;
  - the disclosure is made in accordance with any enactment or Order of a court;
  - the disclosure is necessary or expedient for the purpose of protecting the welfare of any individual;
  - the disclosure is made to any person or body in circumstances where it is necessary or expedient for the person or body to have the information for the purpose of exercising functions of that person or body under any enactment;
  - the disclosure is made for the purpose of facilitating the exercise of any of the Committee's functions;
  - the disclosure is made in connection with the investigation of a criminal offence (whether in Jersey or elsewhere); or
  - the disclosure is made for the purposes of criminal proceedings (whether in Jersey or elsewhere).

### Establishment of the Committee

- 176. The Committee must be constituted in accordance with the law. It must deliver its functions as set out in the law and operate in accordance with its terms of reference.
- 177. The Committee will report directly to the Minister.
- 178. The Committee must be established before the Jersey Assisted Dying Service commences full operations and accepts its first formal requests from any persons."Established" means that:
  - a. the independent Chair must be appointed
  - b. the minimum number of Committee members must be appointed (whether or not they are professional lead members see below)

- c. the Terms of Reference of the Committee must have been adopted by a decision of the Minister (i.e., a written Ministerial decision)
- 179. Establishing the Committee prior to the Service commencing full operations will require the relevant articles of the law to come into force post registration of the law in the Royal Court, with Articles others coming into force by an Act of the States (detail to follow with law drafting instructions on *Commencement*).
- 180. For the purposes of clarity, the terms of reference do not need to be adopted by a decision of the Minister prior to the appointment of the Chair and other Committee members. The appointment process can be undertaken against draft terms of reference and the Committee can commence operating in 'shadow form' but the Committee cannot make any formal decisions until the relevant Articles of the Law are in force.

### Operating in public

181. The Committee is not required by law to hold its meetings, or any part of its meetings in public (although this may be provided for in the terms of reference adopted by the Minister).

### Terms of reference

- 182. The terms of reference (which must be adopted and / or amended by a decision of the Minister) must set out procedures related to the delivery of the Committee's functions (i.e., its operating procedures). This may include, for example, meeting schedule; standing agenda items; voting arrangements.
- 183. Prior to making a decision to adopt the terms of reference (or prior to making any subsequent amendments to the terms of reference), the Minister must consult:
  - a. the Jersey Care Commission
  - b. the Chief Officer of the Health and Community Services Department or equivalent
  - c. the Chair and all other members of the Committee (if appointed)
  - d. the Chair of Health and Community Service Advisory Board (if established)
  - e. any other person who the Minster determines should be consulted.
- 184. The terms of reference must accord with the law (and any associated Orders related to the membership of the Committee)

### Power to amend by Order

- 185. The law should provide that the articles of the law that provide for matters related to the membership of the Committee (as described below) can be amended by Order of the Minister. This includes amending:
  - a. the maximum and minimum number of Committee members
  - b. the appointment and recruitment process
  - c. the description of relevant professional leads who may be members of the Committee
  - d. the description of other relevant members
- 186. This does not include a power to amend by Order any functions of committee. The law should provide, however, that the Assembly may determine by Regulations any amendments to the functions of the Committee, including providing for new functions, or removing existing functions.

### Membership of the Committee

- 187. The law will provide that maximum number of Committee members is 15 and the minimum number of Committee members is 7.
- 188. Committee members must include a Chair, relevant professional leads and other relevant members. The law will not set out the proportion of relevant professional leads to other relevant members as this will be subject to ability to recruit, staff turnover etc.
- 189. The Chair of the Committee must:
  - a. must be an independent person. This means they cannot be a paid employee or a Board member or Charity Trustee / Governor of any entity that provides end-oflife or palliative care services in Jersey, this includes HCS (note: they can volunteer for the entity providing that is not at Board level) or employed by or directly affiliated to any assisted dying campaign group, whether that group supports or is opposed to assisted dying. Where a candidate has a degree of affiliation to an assisted dying campaign group, it will be for the Minister to determine whether the degree of affiliation constitutes direct affiliation
  - b. have demonstrable, significant experience of oversight and assurance of clinical service provision.
- 190. Note: It is envisaged that the Chair of the Committee will also be a Non-Executive Director (NED) of the Health and Community Services Advisory Board, if the Board is established at that time. This may be an existing NED who meets the requirements set out above or may need to be appointed as both Chair of the Committee and an Advisory Board NED. This is however, a matter of policy and does not need to be provided for in law.
- 191. Relevant professional leads (or the equivalent post holders) who may be members of the Committee include:

- a. Chief Officer, HCS
- b. Chief Nurse
- c. Medical Director
- d. Chief Pharmacist
- e. Director of Mental Health & Adults Social Care
- f. Chief Allied Health Professional (or equivalent)
- 192. Law drafting officers are asked to note that the Minister is currently considering some structural changes to the Department which may include a change of name and / or changes to job titles (for example, Chief Executive as opposed to Chief Officer etc.) hence reference to "or equivalent").
- 193. Other relevant members may include:
  - a. representatives from non-HCS services that provide care to people who are at end-of-life, for example; hospice, care homes and home care providers
  - b. persons who have significant, demonstrable experience of oversight and assurance of clinical service provision and who are not an employee of HCS
  - c. patient representatives with lived experience of palliative care and / or end of life care in a personal capacity or by supporting family / friends through the process
  - d. persons with expertise in medical ethics.

### Appointment / recruitment

- 194. The Minister will:
  - a. appoint the Chair after a recruitment process overseen by the Jersey Appointments Commission
  - b. appoint other relevant members by Ministerial Decision (i.e., no requirement for recruitment process overseen by the Jersey Appointments Commission). Prior to appointing other relevant members the Minister must consult the Chair
- 195. Relevant professional leads will be appointed to the Committee by the Chair. A person who is a relevant professional lead cannot refuse to be a member of the Committee as undertaking a governance task related to the general provision of an assisted dying service is not considered to constitute participation in assisted dying.
- 196. Nothing in the law should prevent the Committee seek specialist advice from nonmembers who may attend meetings on a regular or ad hoc basis, for example HCS Associate Director of Quality and Safety.

197. The Minister may determine, by Ministerial Decision, any remuneration provided to the Chair of the Committee or to any other members of the Committee (who are not relevant professional leads).

### Annual report on assisted dying in Jersey

- 198. The law will provide that the Committee will have a duty to make an annual report on assisted dying to the Minister, no later than the 31 March each year, for every full calendar year that the law is in effect.
- 199. The Minister must present the report provided to the States Assembly as soon as reasonably practicable after this date. These requirements are similar to the provisions set out in Prison (Independent Prison Monitoring Board) (Jersey) Regulations 2017.<sup>42</sup>
- 200. The purpose of the annual report is to ensure transparency and to support the identification of any trends or potential issues. For example, potentially identify groups of people with similar characteristics who may be more inclined to request an assisted death which may indicate requirements for changes to existing support or treatment services. However, in providing for this transparency it is essential the report does not allow for identification of individual people, or the circumstances of the deaths of individual people. This is a recognised risk given the small population coupled with the death registration process which is a public process.
- 201. As set out above, one of the functions of the Committee is to compile data and monitor matters related outcomes and numbers and profile of service users. This data is central to the development of the Annual report BUT even where it is determined that this data should not be included in the report, in order to protect against identification of individuals, it is the case that it remains a function of the Committee to compile and monitor the data in order to identify trends and issues even where the information is not included in the report and released in the public domain.
- 202. The law should provide that the annual report must include the following information:
  - a. Total number of assisted dying requests, assessments and approvals including the total number of professional supporting assessments / opinions
  - b. Information on the total numbers of assisted dying appeals, including grounds for appeal and outcome of appeals
  - c. information on total numbers of assisted deaths; by method (self-administered or practitioner administered) and mode (oral or intravenous administration)

<sup>&</sup>lt;sup>42</sup> Prison (Independent Prison Monitoring Board) (Jersey) Regulations 2017 (jerseylaw.je)

- d. Any other matters related to assisted dying, as agreed in consultation with the Medical Officer for Health. For example, numbers of:
  - first formal requests
  - first assessments
  - independent assessments
  - second opinion assessments
  - second formal requests
  - withdrawals of request
  - the uptake of support services for professionals and for family / friends of person requesting assisted dying
- 203. The law will should provide that report should also include the following information but only where the provision of the information does not allow for the identification of individuals or the circumstances of their death (for example; if there is 1 assisted death that year, the report is unlikely to include the following information):
  - a. time between approval granted and assisted death
  - b. reported medical complications during or after administration of assisted dying substance
  - c. a profile of persons requesting an assisted death; approved as eligible for an assisted death, having had an assisted death. 'Profile' in this context means, age, gender, eligible physical medical condition category [e.g. cancer, neurological, respiratory-related]; use of palliative and end of life care at the time of making first request; English as first or additional language; use of interpreting or communication support.
- 204. The Committee must, having consulted the Medical Officer for Health, and having given consideration to the fact that assisted deaths are a matter of public record via the death registration process, must determine if the provision of the information set out in the paragraph above allows for such identification.
- 205. The Committee must:
  - a. prior the commencement of the Service, consult the Medical Officer for Health about:
    - information and data to be included in annual report, over and above that set out in law
    - the methodology for compiling and analysing annual report data
    - the format of the presentation of the annual report data.
  - b. post publication of each annual report, and as soon as is reasonably practicable, consult the Medical Officer for Health about whether, in the opinion of the Medical Officer for Health, there should be changes to the methodology and format for the next annual report.

- 206. The law will also set out that the annual report must not include the names of people requesting / having an assisted death; the names of assisted dying practitioners or other person who has participated in the request and assessment process or the process for accessing assisted dying or any information that would prejudice a criminal investigation or criminal proceeding or any civil proceeding or any proceeding of the Viscount.
- 207. This requirement is similar to provision in Australian laws, for example New South Wales.<sup>43</sup>

### Other reports

- 208. The law will provide that the:
  - a. Committee shall, when requested by the Minister:
    - prepare a report upon an aspect of assisted dying in Jersey, as requested by that Minister; and
    - submit the report to the Minister.
  - b. Committee may prepare a report on any aspect of assisted dying, as it thinks fit. (For example, this may include an interim annual report) and submit that report to the Minister.
  - c. Minister shall publish those reports, and any other information or give such advice to the public regarding the operation of this Law, as the Minister considers appropriate.

## **4.** Health and care professionals

This section details:

- the right of people to refuse to participate in assisted dying
- how professionals must conduct discussions about assisted dying with patients
- the requirement for professionals to register with the Jersey Assisted Dying Service
- the registration process, including qualification and training requirements.

<sup>&</sup>lt;sup>43</sup> <u>Voluntary Assisted Dying Act 2022 No 17 - NSW Legislation</u> – see Article 173 (3) (b)

### Right to refuse to participate in the assisted dying process

209. In debating P95/2021 the Assembly agreed, in principle, that 'the law should provide for a conscientious objection clause so that any registered nurse, medical practitioner or other professional is not under a legal duty to participate in assisted dying.'

### Refusal on any grounds

- 210. Following feedback specifically from the British Medical Association (BMA), the proposals were extended to include a 'right to refuse' to participate in assisted dying on any grounds, as distinct from just conscientious objection.<sup>44</sup>
- 211. The law should provide that no person can be compelled to participate in the assessment, approval or delivery of an assisted death either:
  - on the grounds of conscientious objection i.e. a decision not to participate for reasons of conscience such as moral, ethical or religious beliefs
  - for any other reason for example, the professional's concern about the potential emotional impact on themselves of participating in an assisted death, or for practical or business reasons, for example, concern that their participation may create concerns amongst other clients or patients.

### Defining 'participation in the provision of assisted dying'

- 212. The proposals put to the States Assembly in P18/2024 set out that: "no person should be under a legal duty to participate <u>directly</u> in the provision of assisted dying and any such person will have a right to refuse direct participation"
- 213. The policy intent underpinning this statement was that the law should allow for a person to refuse to participate in assisted dying on an equivalent basis to Termination of Pregnancy (Jersey) Law 1997 / UK Abortion Act 1967 (except that objections should be permitted on any grounds, not just conscientious objection). Whilst the term 'directly' (or 'direct') is not part of the 1997 Law or 1967 Act, it was included in P18/2024 to in order to clarify the interpretation of *participation*. The 2014 the Scottish Supreme Court ruled that the conscientious objection clause in the 1967 Act should be interpretated as being 'narrow' in scope as opposed to 'wide' scope i.e., participation in termination of pregnancy means "actually taking part" or performing the tasks involved in the course of treatment which would broadly include the administration of drugs to induce labour, the medical and nursing care associated with labour and giving birth [i.e. "direct" participation] but would not include, for example, the ordinary nursing or pastoral care of a patient, the associated administrative tasks or the hospital managers who determine how the service is organised.
- 214. The inclusion of the words 'direct' and 'directly' was in response to consultation with the UK Professional regulatory bodies, who were concerned that the lack certainty as to interpretation of the term '*participation*' given the 2014 Supreme Court ruling.

<sup>&</sup>lt;sup>44</sup> <u>bma-letter-to-deputy-tom-binet-feb-2024.pdf</u>

215. The report accompanying P18/2024 went on to set out some examples of 'direct' and 'indirect' participation in relation to assisted dying. For example, being present at the time of administration of the assisted dying substance, or directly supporting the administration would be considered as 'direct participation', whereas booking an appointment for a supporting assessment would be considered 'indirect participation'.<sup>45</sup>

### Removal of word 'direct' from 'direct participation'

- 216. P18/2024 was, however, amended by the Scrutiny Assisted Dying Review Panel, with the words 'direct' and 'directly' being removed from the proposition. The rationale for removal of the words 'direct' and 'directly', was set out in the amendment report presented by the Review Panel as: *"the inclusion of the terms 'direct' and directly' is unclear and may unduly restrict the right to refuse participation in assisted dying. The Panel believes it is important that all persons within the purview of assisted dying have the right to refuse to participate and that the meaning of "participate", defined by the Oxford English Dictionary as "To take part; to have a part or share with a person, in a thing", is sufficient wording on its own."<sup>46</sup>*
- 217. Therefore, in accordance with the Assembly's decision, the Law should not seek to define what is meant by direct participation. However, as per other Assisted Dying Laws (See Victoria and Western Australia<sup>47,48</sup>) the Law should set out:
  - what constitutes participation for purposes of the right to refuse provision, and
  - that the right to refuse only extends to matters that constitute participation in assisted dying.

### What constitutes participation for the purposes of the right to refuse?

- 218. Participation in assisted dying means, for the purposes of the right to refuse, a right to refuse to do any of the following:
  - a. to apply to register as an assisted dying practitioner or ADRMP
  - b. to be registered as an assisted dying practitioner or ADRMP
  - c. to practise as an assisted dying practitioner (or ADRMP), which includes undertaking any duties of assisted dying practitioners (or ADRMP) as set out in the assisted dying law and associated guidance
  - d. to undertake a supporting assessment to inform an assessing doctor's determination of eligibility for an assisted death (for example, pulmonary function

<sup>&</sup>lt;sup>45</sup> <u>p.18-2024.pdf (gov.je)</u> – see paragraphs 93-96

<sup>&</sup>lt;sup>46</sup> p.18-2024 amd.pdf (gov.je)

<sup>&</sup>lt;sup>47</sup> <u>Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au)</u> – Article 7

<sup>&</sup>lt;sup>48</sup> Voluntary Assisted Dying Act 2019 - [00-00-00].pdf (legislation.wa.gov.au) – Article 9

tests, carried out by a physiotherapist or an assessment to determine decisionmaking capacity by a psychiatrist or psychologist)

e. to provide supporting opinion to inform the assessing doctor's determination of eligibility for an assisted death (for example: a domiciliary care worker's opinion on the voluntary and settled nature of the person's wish)

Note: right to refuse does not extend to the provision of pre-existing information whether or not that is medical information, for example, proof of residency information.

- f. to provide communication support to a person as part of the assisted dying process (see section *Communication support and advocacy*)
- g. to apply to be appointed as a Care Navigator, or to be appointed as a Care Navigator or to practise as a Care Navigator

Note: it was originally envisaged that the right to refuse would include a right to refuse to undertake any of the specific roles, however, as there are tasks that will fall to someone undertaking a specified role that may also fall to a person who is not undertaking a specific role (for example, booking an appointment), we have formulated the right to refuse as being applying to register / to be appointed or being registered / being appointed as an assisted dying practitioner or Care Navigator as distinct from a right to refuse to undertake a specified role.

- h. to be present at the time of the administration of the assisted dying substance
- i. to be present at the time for preparations directly required for the administration of the substance (for example, setting up of IV lines) or to assist in those preparations. This is required if, for example, the assisted death is taking place in the hospital.
- j. to provide information about assisted dying to a person who is seeking information about assisted dying
- k. to provide information about assisted dying when advising a person about treatment options for their condition or illness.
- 219. Previous rulings by the UK Supreme Court have clarified that doctors have a duty to raise treatment options with patients specifically McCulloch v Forth Valley Health Board which set out that "a doctor is under a duty to take reasonable care to ensure that the patient is aware of … any reasonable alternative or variant

treatments."<sup>49</sup> Given this, the assisted dying law should be explicit that any duty to advise on treatment options does not extend to advising a person on any matter related to assisted dying, including the fact that assisted dying is available in Jersey (except for where the person is an assisted dying practitioner, where they must clearly advise on assisted dying alongside advising on treatment options). This is because in the context of providing advice on treatment options, assisted dying should not be regarded as a treatment.

- 220. Where a health and care professional, in advising a patient about treatment options, chooses not to provide information about assisted dying to a person and that person has not asked about assisted dying the professional is not required to tell them they are exercising their right to refuse because, to do so, would be tantamount to raising the issuing of assisted dying. This does not, however, preclude the professional from raising the issue of assisted dying, even when the person has not sought the information. (See Section on *Discussion of Assisted Dying* below)
- 221. Where a person who is a health and care professional exercises their right to refuse to provide information about assisted dying to a person who is seeking information about assisted dying the health and care professional should:
  - inform the person they are exercising their right to refuse;
  - inform the person that the Jersey Assisted Dying Service may be able to assist; and
  - inform the person how they may find out details of how to contact the Jersey Assisted Dying Service (Note: it is intended that the Service will supply to all GPs and other key providers leaflets setting out the Jersey Assisted Dying Service contact details. In the event the health and care professional does not have access to the leaflet, they can inform the person to look online)
- 222. Where any other person declines, who in the course of their employment (whether or not paid employment) or duties is asked to provide information about assisted dying to a person who is seeking information about assisted dying they are not required by law to explain their reasons for not doing so (although it may be a condition of their employment).
- 223. Where a person fails to comply with the requirement above, they will not have committed an offence under law.
- 224. The right to refuse to participate is, in some jurisdictions restricted to health and care practitioners. It is intended that, in Jersey Law, the right to refuse is provided to any person in their course of their employment (whether or not paid employment) or duties, except for where they are an assisted dying practitioner or Care Navigator. (For example, if a cleaner or porter was asked to be present at the administration of the substance, they could refuse to do so).

<sup>&</sup>lt;sup>49</sup> McCulloch and others (Appellants) v Forth Valley Health Board (Respondent) (Scotland) - The Supreme Court

- 225. Participation in assisted dying (for the purposes of the right to refuse) is not intended to include participation in / delivery of the following tasks, and hence the right to refuse to participate does not intended to extend to these tasks:
  - a. providing usual nursing, medical, personal care or ancillary services to a person who has requested an assisted death, or who has had an assisted death. For example:
    - a care home could not refuse to care for a resident because that resident has requested an assisted death
    - an ambulance or patient transport driver could not refuse to transport a patient to an assisted dying appointment
    - an administrator could not refuse to book an appointment for a person who has requested an assisted death
    - a cleaner could not refuse to clean the room in a hospital where an assisted death has taken place
    - a porter / mortician / undertaker could not refuse to care for the body of the deceased
  - b. management or governance or ancillary tasks related to the general provision of an assisted dying service. For example:
    - act as a Responsible Officer for an assisted dying doctor
    - act as chair or committee member for the Assurance and Delivery Committee
    - act as panel member for the Assisted Dying Review Panel
    - undertake financial planning tasks associated with the delivery of the service
    - process and analyse statistical information about the performance of the Assisted Dying Service
    - cleaning the offices of Assisted Dying Service.

### Note

A person requesting an assisted death would have a right to privacy and patient confidentiality. Therefore, in many cases, a service provider would not know, in any event, if the service they are providing is potentially associated with an assisted death (for example, if a person is being transported to hospital for an assisted dying assessment, this would not need to be known by the person driving them). Similarly, a person ordering medical equipment such as a syringe pump, would likely not be aware that equipment is being ordered for the purpose of an assisted death).

Furthermore, in many cases, the employment contracts of individual and / or professional standards may prevent a person from undertaking one of the tasks set out above, even where it is related to an assisted death.

- c. providing pre-existing information about the patient on request where a person holds that information (for example, test results, notes on prognosis etc). This would not constitute participation in the provision of assisted dying, and a person would not be covered by a right to refuse to participate. [In any event pre-existing information would generally be held on a patient's medical record, and they would be able to make a Subject Access Request under the Data Protection (Jersey) Law 2018, in order to view any information that is held about them.]
- 226. The list of tasks described above is not an exhaustive list. It is for illustrative purposes and would include other comparable tasks. This list will be included in the Right to Refuse & Conscientious Objection Guidance (see below) but the law drafting officer is asked to consider the appropriateness of including it on the face of the Law in order to provide certainty as to the limits on the Right to Refuse.
- 227. In providing for a right to refuse it is imperative that there can be no circumstances in which providers of services can refuse to withhold the <u>usual</u> nursing, medical, personal care or ancillary services to a person who has requested an assisted death, or who has had an assisted death
- 228. Therefore, as above, the right to refuse does not extend to withdrawing care provision for a current service user of a care home or domiciliary care provider. Which, in addition, would likely be a breach of *Regulation of Care (Standards and Requirements)* (*Jersey) Regulations 2018*, by the care provider. However, such protection against the right to refuse may not extend to <u>potential/future service users</u> it is therefore foreseeable that a care home (or domiciliary care) provider may not be considered to breach the Regulation of Care 2018 Regulations by refusing to take in a person who, for example, expresses a wish for an assisted death, *for that reason*.
- 229. If it was to transpire that people who wanted an assisted death could not access the residential or domiciliary care support they require, as all providers didn't accept them, the law should provide for a Regulation making power, to bring amendments to this law and consequential amends to the Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018 and any other relevant legislation, to ensure potential service users cannot be denied access to care home and domiciliary care services on the basis of their views on assisted dying or a wish for an assisted death.
- 230. Whilst the law will set out what constitutes participation in assisted dying it is clearly the case that it is not possible to anticipate all the different facts or circumstances that may arise, therefore the Courts may be required to determine, based on the specific facts of individual case, whether an action or activity does constitute participation and, therefore, whether a person has right to refuse participate.

### Right to Refuse & Conscientious Objection Guidance

- 231. The law will require that the Committee make arrangements for the development of *Right to Refuse & Conscientious Objection Guidance*, which the Committee must publish.
- 232. The primary purpose of the document is to provide guidance to people who choose not to participate (as per their right to refuse).
- 233. The Guidance will:
  - a. set out information related to the right to refuse (i.e., the duties, activities for actions to which it does or does not apply)
  - guide people, who are exercising the right to refuse, in their decisions on how to interact with people who want information about assisted dying or who have requested an assisted death / are considering requesting an assisted death
- 234. The Guidance must have regard to all relevant codes of practice / standards on matters related to conscientious objection or related matters that are issued by professional regulatory bodies and apply to some categories of health and care professionals (for example, professionals registered with the GMC and NMC)
- 235. The Committee must, prior to publication of the guidance, consult the Minister, all relevant professional registration bodies and any other entities or persons that the Committee deems are relevant to consult.
- 236. The Right to Refuse & Conscientious Objection Guidance will stipulate that the care professional:
  - a. must not unfairly treat a person who wants information about assisted dying / is considering having an assisted death / has requested an assisted death, including denying that person access to appropriate medical treatment or services
  - b. must not express their personal beliefs on assisted dying to the person in a way that exploits their vulnerability or are likely to cause them distress.
  - c. must, in accordance with the law:
    - inform the person they are exercising their right to refuse
    - inform the person that the Jersey Assisted Dying Service may be able to assist, and
    - inform the person how they may find out details of how to contact the Jersey Assisted Dying Service (Note: it is intended that the Service will supply to all GPs and other key providers leaflets setting out the Jersey Assisted Dying Service contact details. In the event the health and care professional does not have access to the leaflet, they can inform the person to look online)

- 237. Note: Whilst not prescribed in the assisted dying law, where the health and care professional is registered with a professional regulatory body they will, in any event, need to operate in accordance with any professional standards the body (and any other relevant body) has in place with regard to conscientious objection, as failure to do so may result in a referral being made to their professional regulatory body.
- 238. For the purposes of clarity, it will not be an offence <u>not to comply</u> with the Right to Refuse & Conscientious Objection Guidance. However, depending on the circumstances, a failure to comply may lead to a referral to a professional regulatory body if the fitness to practise concerns could amount to a serious departure from their professional standards. It may also result in investigation by an employer.

### Right to refuse – care homes

- 239. The right to refuse will be extended allow premises operators who are registered providers of adult care home services, and children's residential services (where a person aged 18 or above is resident) to refuse to allow an assisted death to take place in the residential facility, where the services is regulated by the Jersey Care Commission under the Regulation of Care (Jersey) Law 2014. This includes care homes, nursing homes and any other form of regulated residential care provision.
- 240. However, this right will not extend to any Government of Jersey premises, including adult care home services regulated by the Jersey Care Commission under the Regulation of Care (Jersey) Law 2014, where the Government of Jersey is the premises operator.
- 241. The right for premises operators to object to assisted dying, only extends to the provision of an assisted death on the premises. It does not extend to objecting to other steps in the assisted dying process taking place on their premises such as making a request for an assisted death, having an assessment, or the approval or planning of an assisted death. (For example, a resident of a care home must be allowed to have an eligibility assessment or assisted death care planning meeting on the premises, but the care home provider may choose not to permit a resident to have an assisted death in their room).
- 242. In some cases, premises operators will support their residents or patients end-of-life wishes and allow for an assisted death on their premises but, if they choose not to, the Jersey Assisted Dying Service would liaise with the person to identify a suitable alternative location.
- 243. This right to refuse will not extend to landlords of rented dwellings as defined by Public Health and Safety (Rented Dwellings) (Jersey) Law 2018, where the owner is not an

occupier of the property i.e., a landlord cannot prevent their tenant from having an assisted death in the property they rent. The rationale for allowing the right to refuse an assisted death on the premises of a care home (other form of regulated residential care provision), is that the registered provider may need to take in consideration the impact of an assisted death on the premises on other staff and other residents. The same considerations do not apply to private landlords.

- 244. On a practical level, the premises operator will be able to exercise their right to refuse, by not consenting to an assisted death taking place on their premise when asked for their consent by Administering Practitioner as part of the process for location approval (see section *Approval of location*)
- 245. Where the person is ordinarily resident in a property that has multiple occupants (whether or not those occupants are members of the same family and / or include lodgers and boarders), the law will not provide those occupants individually or collectively a right to refuse for an assisted death to take place in that property BUT the Administering Practitioner, having given consideration to the objections of some occupants may refuse to approve the location for an assisted death. Note: this will not include residents of nursing home as it is for the premise operator to make the determination in care homes.
- 246. For detail on the approval of a location for an assisted death, see section *Approval of location*.

### Discussion of assisted dying with patients

- 247. As set out above, the law will explicitly state that a person has a right to refuse to provide information about assisted dying to:
  - a. a person who is seeking information about assisted dying, or
  - b. when advising a person about treatment options for their condition or illness.
- 248. But other than those provisions the law will neither:
  - a. require health and care professionals to raise the subject of assisted dying with a person whom the professional thinks may be eligible for an assisted death, nor
  - b. prohibit health and care professionals from talking to their client / patient about assisted dying, in the context of the person's care and treatment options, even where the person did not raise the subject in the first instance.
- 249. Whilst assisted dying should never be 'recommended', health and care professionals do need to be able to engage in open and informed conversations about end-of-life options which may, in some cases, include assisted dying. There is a balance to be struck between the risk that a patient may feel that assisted dying is being suggested to them as a preferred option, and the risk that a patient is unable to have an informed discussion with a trusted professional about their end-of-life options, or the risk that a cacess to information is inequitable.
- 250. Whilst an explicit requirement to tell people about assisted dying may improve equity of access to information, it may also have unintended consequences, particularly around:
  - a. the sensitivity and nuance as to when is the best time for a conversation about assisted dying
  - b. the doctor-patient relationship and fine balance of a practitioner providing a patient with relevant information vs. being perceived to make a recommendation.
- 251. Both the Nursing and Midwifery Council (NMC) and the General Medical Council (GMC) in their written responses to the Phase 2 consultation supported the position that the law neither requires nor prohibits health and care professionals raising the issue of assisted dying with clients / patients, and supported the development of training and guidance on this matter.

### Note: approach in other jurisdictions

- 252. The laws in Canada and certain US states are 'silent' on this matter, and neither prohibit or require a health and care professional to raise the subject.
- 253. In New Zealand, the law actively prohibits all health professionals from initiating any discussion, though it is understood this position will be considered in a 2024 review of the legislation as it is perceived by some as a 'gagging' clause which gives rise to two key disadvantages:

- a. it can generate uncertainty and confusion amongst professionals as to whether the topic is being raised by a patient or not, which results in a reluctance to discuss the topic openly
- b. it creates an inequality in access to information for certain groups particularly those with English as an additional language and those with additional communication support needs.

### Appropriate conversations guidance

- 254. The law will require that the Committee make arrangements for the development of Appropriate conversations *Guidance*, which the Committee must publish.
- 255. The primary purpose of the document is to provide guidance to any health and care professionals about how manage conversations with patients around assisted dying. It will provide guidance as to:
  - a. the circumstances in which it may be appropriate to raise the issue of assisted dying, even the person has not raised the subject
  - b. the circumstances in which it may not be appropriate to raise the issue
  - c. When a discussion is initiated by the professional (as distinct from the patient) they should, at the same time (and to the extend they have the necessary information and knowledge) inform the patient about:
    - the treatment options available to the person and the likely outcomes of that treatment; and
    - the palliative care and treatment options available to the person and the likely outcomes of that care and treatment.
- 256. In Queensland<sup>50</sup> there is a requirement in law for a health and care professional who initiates a discussion about assisted dying with a patient, to inform the person, at the same time, about:
  - the treatment options available to the person and the likely outcomes of that treatment; and
  - the palliative care and treatment options available to the person and the likely outcomes of that care and treatment.
- 257. This requirement on the health and care professional does not extend to circumstances where it is the person who initiates the discussion about assisted dying.

258. It was decided to include in Guidance, as opposed to Law in Jersey, on the basis that the professional may not have the appropriate information or expertise to provide accurate information about treatment options in the context of a general discussion

<sup>&</sup>lt;sup>50</sup> Voluntary Assisted Dying Bill 2021 (legislation.qld.gov.au) – Article 7

(note: the law will place a duty on the Assessing Doctors to ensure information about treatment options is provided in full, even though this requirement should also have been fulfilled by the person's lead doctor.

- 259. The Guidance will set out that there is nothing that:
  - a. prevents the health and care professional discussing the matter if the patient raises the issue themself (other than the professional exercising their right to refuse or a professional's judgement as to the potential vulnerability of the patient)
  - b. compels the health and care professional from discussing the matter but in accordance with the Law, if they are exercising a right to refuse they must:
    - inform the person they are exercising their right to refuse
    - inform the person that the Jersey Assisted Dying Service may be able to assist, and
    - inform the person how they may find out details of how to contact the Jersey Assisted Dying Service (Note: it is intended that the Service will supply to all GPs and other key providers leaflets setting out the Jersey Assisted Dying Service contact details. In the event the health and care professional does not have access to the leaflet, they can inform the person to look online)
- 260. The Guidance must have regard to all relevant codes of practice / standards on matters related to conscientious objection or related matters that are issued by professional regulatory bodies and apply to some categories of health and care professionals (for example, professionals registered with the GMC and NMC).
- 261. The Committee must, prior to publication on the guidance, consult the Minister, all relevant professional regulatory bodies and any other entities or persons that the Committee deems are relevant to consult.
- 262. For the purposes of clarity, it will not be an offence not to comply with the Appropriate Conversations Guidance. However, depending on the circumstances failure to comply may lead to action or investigation by an employer or a referral being made to a professional regulatory body if it could amount to a serious departure from their professional standards.
- 263. In addition to publishing guidance, the law will require the Committee makes arrangement for the development of an Appropriate Conversations training programme. The training will be provided in a manner and at a time as determined to be appropriate by the Committee. The training will be available free of charge to health and care professionals who are providing health and care services in Jersey and who elect to attend the training. (Note: is will also form part of the mandatory training for assisted dying practitioners)

### Health and care professionals' involvement in assisted dying

- 264. As set out in Section 3, the law will provide that no person or entity other than the Jersey Assisted Dying Service can provide assisted dying in Jersey.
- 265. Assisted dying practitioners must, therefore be engaged by the Jersey Assisted Dying Service. Where that service is provided by HCS, this means HCS will need to engage assisted dying practitioners and the Care Navigator either via a contract of employment or a contract for services that enables them to work in the Jersey Assisted Dying Service. Where assisted dying practitioners are on contracts of employment it is envisaged that their work in the Assisted Dying Service will only form one part of their job role (Note: this is contractual matter, not a matter for law).
- 266. The law will provide that, in order to work for the Jersey Assisted Dying Service, the professional must register as an assisted dying practitioner. (Note: this does not include the Care Navigator, but it does include the ADRMP)
- 267. The Committee will make arrangements to establish a register of assisted dying practitioners and ADRMP, which will be maintained by the Jersey Assisted Dying Service. [See Sections on *functions of the Jersey Assisted Dying Service, functions of the Committee*, and the Section on *Registration as an assisted dying practitioner*]

### Assisted dying practitioners

- 268. The law will provide for the following 'assisted dying practitioner' roles (listed in 'Terms used') who will be engaged to deliver the Jersey Assisted Dying Service:
  - a. **Coordinating Doctor** the doctor who: undertakes the first assessment of the person who has requested an assisted death, coordinates the assessment process; makes the decision to approve or refuse the person's request.
  - b. **Independent Assessment Doctor** the doctor who undertakes the independent assessment of the person who has requested an assisted death.
  - c. **Second Opinion Doctor** the doctor who undertakes a second opinion assessment if the person makes a request for a second opinion assessment and that request is accepted (a second opinion assessment may be requested after the first or independent assessment)
  - d. **assessing doctors** the Coordinating Doctor and the Independent Assessment Doctor (plus the Second Opinion Doctor, where relevant) are collectively referred to as "assessing doctors". They will assess the person who has requested an assisted death to determine if they meet the eligibility criteria.

- e. **Multidisciplinary team (MDT) member** an MDT will be formed to support the assessment process for each person who requests an assisted death. In addition to the assessing doctors, the MDT may include a registered nurse (level 1), social worker and any relevant allied health professionals (e.g., a speech and language therapist).
- f. **Pharmacy Professionals** pharmacists and pharmacy technicians who have registered with the Jersey Assisted Dying Service. Will prepare and dispense the substance used in assisted dying, will work within the Hospital Pharmacy.
- g. **Administering Practitioner** the doctor or registered nurse who will administer the substance used in assisted dying or support the person to self-administer the substance.

### Other roles

- 269. In addition, to assisted dying practitioners, other professionals will be engaged to deliver / support delivery of the Jersey Assisted Dying Service. These roles include:
  - a. non-clinical staff such as administrators. There will be no reference to these staff in the law (except that the law should not in any way prohibit such staff being engaged in the delivery of the Jersey Assisted Dying Service)
  - b. Care Navigators. The Care Navigator is not an assisted dying practitioner and hence does not need to be registered as an assisted dying practitioner, but the Care Navigator does have some specific tasks to undertake in the assisted dying process and therefore does need to be provided for on the face of the law
  - c. Assisted Dying Registered Medical Practitioner" (ADRMP). The ADRMP must be registered with the Jersey Assisted Dying Service as an ADRMP. Any person so registered is prohibited from also being registered as an assisted dying practitioner OR from being engaged as a Care Navigator. This is because of the need to ensure that the ADRMP who certifies a person's assisted death was not involved in the assessment or approval processes that facilitated that death.

### Competency frameworks, training and qualifications

### Competency frameworks

- 270. The law will provide that it is a function of the Committee to make arrangements for the development of competency frameworks, to approve the frameworks and to make available to the relevant persons.
- 271. The competency frameworks will set out the skills, knowledge and behaviours required to practise as an assisted dying practitioner or ADRMP. This must include the following core frameworks:
  - an Assessing doctor competency framework

- a Pharmacy professional competency framework
- an Administering Practitioner competency framework
- a Multidisciplinary team member competency framework
- an Assisted Dying Registered Medical Practitioner competency framework

Note: there is no requirement for a Care Navigator competency framework as the Care Navigator is not a registered assisted dying practitioner, and they will be employed / engaged against a job description.

- 272. The law will provide that the Committee:
  - a. may also develop, approve and publish other frameworks or sub-sets of the core frameworks as the Committee deems necessary (for example, the Committee may determine that the Assessing Doctor competency framework who consist of a Coordinating Doctor Framework and an Independent Doctor competency framework)
  - b. amend the frameworks as the Committee deems necessary.
- 273. In developing or amending the competency frameworks the Committee must consult with the entities or persons that the Committee deems are relevant to consult, for example the UK professional regulatory bodies and professional membership organisations.
- 274. The frameworks must set out, for each role, requirements related to:
  - a. skills (including practical skills, communication and interpersonal skills, and clinical skills), knowledge and expertise
  - b. training (other than assisted dying training) and professional qualifications
  - c. capabilities for example safeguarding vulnerable groups, patient safety and legal and ethical aspects of care
  - d. values and behaviours
  - e. registration with the JCC, or another appropriate Jersey Body
  - f. registration with a UK regulatory body and period of registration

### Assessing doctor

- 275. The competency framework for an Assessing Doctor (Coordinating Doctor, Independent Assessment Doctor or Second Opinion Doctor) will provide that the person must be a doctor who is:
  - a. registered with the JCC as a doctor, and

- b. registered with the GMC as a doctor for the period prescribed by Order of the Minister [see below *Prescribed period of registration*].
- 276. Note: Assessing Doctors are not required to be an expert / specialist in the medical condition of the persons they are assessing for an assisted death but, they must seek opinion of experts as required [see below *Prescribed period of registration*].

### Administering Practitioner

- 277. The competency framework for an Administering Practitioner will provide that the person must be:
  - a. registered with the JCC as a doctor, and registered with the GMC for the period prescribed by Regulation by the Minister or
  - b. be registered with the JCC as a nurse and registered with the NMC for a period prescribed by Order the Minister [see below *Prescribed period of registration*].
- 278. It is anticipated that the roles of physician associates (PAs) and anaesthesia associates (AAs) will, in future, be GMC registered professions and, subject to Assembly agreement, also be able to register with the JCC. The law should provide that, at this point in time, PA and AA should be able to register as Administering practitioners, providing the meet all the assisted dying registration requirements for Administering Practitioners.

### Pharmacy Professional

- 279. The competency framework for a Pharmacy Professional will provide that the person must be a dispensing pharmacist or pharmacy technician who is:
  - a. registered with the appropriate body in Jersey as a dispensing pharmacist or pharmacy technician (the appropriate body is currently the Chief Pharmacist but, pending development of a proposed new Professional Registration Law, with the JCC)
  - b. registered with the GPhC as dispensing pharmacist or pharmacy technician for a period prescribed by Order of the Minister [see below *Prescribed period of registration*].

### Multidisciplinary Team members

- 280. The competency framework for Multidisciplinary Team members will provide that the person must be:
  - a. registered with the appropriate body in Jersey (for example, the JCC) and
  - b. registered with the GMC/NMC/HCPC or other relevant professional registration body for a period prescribed by Order of the Minister [see below *Prescribed period of registration*].

281. In the case of Multidisciplinary Team members, the appropriate body in Jersey and the UK may vary depending on the profession of the team member

#### Assisted Dying Registered Medical Practitioner (ADRMP)

- 282. The competency framework for an ADRMP will provide that the person must be a doctor who is:
  - a. registered with the JCC as a doctor, and
  - b. registered with the GMC as a doctor for the period prescribed by Order of the Minister [see below *Prescribed period of registration*].

#### Prescribed period of registration

- 283. The law will provide that the Minister must prescribe, by Order, the minimum period of registration that an Assessing Doctor, Administering Practitioner, Pharmacy Professional or Multidisciplinary Team members or ADRMP must be registered with the relevant UK regulatory body. Prior to making this Order, the Minister must consult the Committee, the JCC and the relevant professional regulatory body, plus any other person or entity that the Minister deems should be consulted.
- 284. Note: For the purpose of these instructions, it is set out that the period will be prescribed by Order but the Lawdrafting Officer asked to consider the most appropriate arrangements.

#### Assisted Dying training

285. The law will provide that it is a function of the Committee to make arrangements for the development of the assisted dying training programme (and an associated refresher

training programme), to approve the training programme / refresher programme and to make available to the relevant persons.

- 286. The training programme must:
  - a. address matters relevant to all assisted dying practitioners and Care Navigators, for example:
    - the assisted dying legislative provisions
    - the assisted dying process
    - the requirements and duties, competencies for each role
    - professional guidance and all policies developed by the Assurance and Delivery committee
    - risk
    - assisted dying practitioner safety and wellbeing
  - b. provide, where required, specific modules for differing role that address the necessary technical knowledge necessary to undertake that role, for example: an Administering Practitioner module providing specific technical training on the administration of the assisted dying substance
  - c. include a specific module on Death Certification for Assisted Dying
- 287. The matters relevant to all practitioners / Care Navigators must include detailed information on determining on voluntary nature of the person's request (i.e. an absence of coercion) as this is pertinent to any practitioner who has contact with a person who has request and assisted death.

- 288. It is a requirement of registration as an assisted dying practitioner to successfully complete the assisted dying training programme (and refresher programme)
- 289. The Care Navigator who is not an assisted dying practitioner and does not need to be entered onto the register must also successfully complete the assisted dying training programme (and refresher programme).
- 290. The ADRMP will be required only to undertake the training modules relevant to their role in the death certification process.

#### Registration as an assisted dying practitioner

- 291. The law will set out that the Jersey Assisted Dying Service shall maintain a register of an assisted dying practitioners on behalf of the Committee. The purpose of registration is to ensure there is a record of appropriately qualified professionals who may work for the Jersey Assisted Dying Service.
- 292. No person can hold themselves out as an assisted dying practitioner in Jersey unless they are on the assisted dying register. (See instructions to follow on Offences)
- 293. The law will set out the:
  - a. registration requirements
  - b. registration arrangements including:
  - the information entered onto the register
  - process of registration and entry onto the register
  - registration renewal procedures
  - suspension and cancellation of registration procedures
  - the powers and duties of the Jersey Assisted Dying Service to share information with other relevant bodies (for example, UK professional regulatory bodies, States of Jersey Police) about registered professionals.

#### **Registration requirements**

- 294. In order to be registered as an assisted dying practitioner or ADRMP the professional must meet all the registration requirements. This includes that the Committee determines on the recommendation of Assisted Dying Service that, the professional:
  - a. is a fit person to be registered as an assisted dying practitioner. This means the person is a fit person do carry out the duties of an assisted dying practitioner and has not declared any interest that may make them unsuitable to be registered as an assisted dying practitioner (see section *Registration declaration*)
  - b. meets the requirements of the relevant competency framework. This includes:
    - having the necessary skills, knowledge and expertise
    - being registered with the JCC or the relevant Jersey registration body
    - being registered with the appropriate UK regulatory body for the prescribed length of time
  - c. must have completed the assisted dying training programme prior to registration
    - Note: the practitioner must also must undertake the assisted dying refresher training programme within three years of the date they completed the assisted dying training programme, and then every 3 years from the date of completion of the refresher training.
    - the professional will be required to complete their refresher training prior to the end of a the 6-month 'grace period' following the date that is three years after their original training or previous refresher training (i.e., there is a grace period for the 3-year refresher requirement, where the professional can continue to act and be registered as an assisted dying practitioner before they are removed from the register. This allows for unforeseen circumstances that prevent the completion of refresher training, for example, exceptional work commitments, or accidental failure to complete the refresher training in a timely fashion)
    - In the case of an ADRMP they only need to have completed / renewed the training module related Death Certification for Assisted Deaths

295. The law must provide that a doctor may not be registered as an assisted dying practitioner or ADRMP if, at the point of registration, the doctor does not have a named responsible officer for the purpose of GMC revalidation.

#### Information entered onto the Register

- 296. The law will provide that the following information must be entered onto the register for each registered professional:
  - a. the professional's name
  - b. name of their UK professional regulator and UK registration number (where applicable)
  - c. their Jersey Care Commission registration number (where applicable, or other equivalent Jersey registration for example Pharmacy Professionals will be required to provide confirmation of registration with the Chief Pharmacist)
  - d. any declared conflicts interest
  - e. their assisted dying service role/s (e.g.: Assessing Doctor, Pharmacy Professional, Administering Practitioner, Multidisciplinary team member, ADRMP)
  - f. the capacity in which they are engaged to work in the Service (: HCS employee; contract for service)
  - g. date / s of successful completion of Assisted Dying training / required Assisted Dying Training modules and dates of any refresher training undertaken
  - h. date of next scheduled refresher training
  - i. date of initial entry onto the Assisted Dying register
  - j. date /s of annual renewal of entry onto the Assisted Dying register
  - k. date of removal from assisted dying register
  - I. reason for removal from register, e.g.:
    - failure to submit annual renewal
    - practitioner requested cancellation of registration.

297. The law will also provide that the Minister may, by Order, amend the information to be held on the register, having consulted the Committee and any other person or entity the Minister deems relevant, about the requirement to make such an amendment.

#### Process of registration and entry onto the registration

- 298. A person who wishes to practice as an assisted dying practitioner must apply to be registered as an assisted dying practitioner.
- 299. The application to register should be in the form required by the Committee. It must:
  - a. contain all the information to be entered onto the register (including where provided for by Order of the Minister)
  - b. contain any other information that the Committee determines is required by the Service to process and determine the application
  - c. be accompanied by such information the Committee determines is required by the Service to process and determine the application
  - d. contain a declaration, signed and dated by the applicant, that the information contained in the application is, and the documents accompanying the application are, true and complete, to the best of the applicant's knowledge and belief.
- 300. A doctor may be registered, and apply to be registered as:
  - a Coordinating Doctor, and / or an assessing doctor who is not a Coordinating Doctor (in the event they are happy to undertake independent assessments or second opinion assessments but do not wish to take on the additional duties of the Coordinating Doctor) and / or an administering practitioner and /or an MDT member, OR
  - b. as and ADRMP (i.e., a doctor who is an ADRMP cannot be registered as an assisted dying practitioner.)
- 301. The Jersey Assisted Dying Service may only enter a person onto the register, on behalf of the Committee, where the Service is satisfied that the person fulfils all of the registration requirements set out in detail above.
- 302. For the purpose of clarity, the Jersey Assisted Dying Service:
  - must enter a person onto the register if they are satisfied they fulfil all the registration requirement
  - may refuse to enter the person onto the register if they are not satisfied that they fulfil all the registration requirements.

303. In making their determination if all the registration requirements are fulfilled, the Jersey Assisted Dying service may cross-reference the information provided by the applicant for registration with information retained about them by other relevant bodies

#### Renewal of registration

- 304. The law will provide that assisted dying practitioners must renew their registration on an annual basis. However, ADRMP will not be required to renew their registration annually.
- 305. To renew their registration a professional must complete, sign and date a registration renewal form which they must submit to the Jersey Assisted Dying Service within 3 months from the scheduled date of annual renewal (i.e., there is a grace period of where the professional can continue to act and be registered as an assisted dying practitioner before they are removed from the register. This allows for accidental failure to renew in a timely fashion)
- 306. The registration renewal form will in the form required by the Committee and be accompanied by such information as the Committee requires and will require the person to re-confirm their declaration of interests.
- 307. A professional who does not renew their registration must be removed from the register by the Jersey Assisted Dying Service as soon as practically possible after the 3-month period after the scheduled date of annual renewal has elapsed.
- 308. The Assisted Dying Service must inform the professional in writing before removing them from the Register for failure to renew.
- 309. For the purposes of clarity, a practitioner whose registration has lapsed through failure to renewal may be re-registered by the Jersey Assisted Dying Service providing they still meet all the registration requirements.

#### Changes to registration information

- 310. The law will provide that a person registered as an assisted dying practitioner or ADRMP will commit an offence if they fail to inform the Service that their registration with the JCC or relevant UK regulatory body has been suspended or cancelled (see instructions to follow on Offences).
- 311. The law will also provide that:

- a. registered practitioners should advise and update the Jersey Assisted Dying Service if there have been any changes to the details held by the register, outside of the renewal period
- b. on receipt of such information the Jersey Assisted Dying Service should update the register as soon as practically possible.
- 312. It is not intended that there are any penalties associated with failure to inform the Service of changes to registration information other than failure to inform of suspension or cancellation of JCC or UK regulatory body registration.

#### Cancellation / suspension of registration

- 313. An assisted dying practitioner or ADRMP may at any time cancel their registration as an assisted dying practitioner. They must inform the Jersey Assisted Dying Service who must remove them from the register as soon as practicable after being so informed.
- 314. The Jersey Assisted Dying Service must suspend a professional's registration as an assisted dying practitioner or ADRMP, if that person's registration with the JCC and/or their relevant professional body is suspended.
- 315. The Jersey Assisted Dying Service must cancel a professional's registration as an assisted dying practitioner or ADRMP, if that person's registration with the JCC and/or their relevant professional body is cancelled.
- 316. The Jersey Assisted Dying Service may also cancel or suspend a professional's registration as an assisted dying practitioner or ADRMP if:
  - a. they are found not to have met all the registration requirements, including completion or renewal of the mandatory training
  - b. any fitness to practise issues arise and where either the JCC or the practitioner's UK professional regulatory body has been notified, including if as a result of their work for the Jersey Assisted Dying Service or any other activity carried out as a health and care professional.
- 317. As the Jersey Assisted Dying Service maintains the register on behalf of the Committee, and enters professionals on behalf of the Committee, all suspensions and cancellations are also on behalf of the Committee (except for where the practitioner has cancelled their own registration). The Jersey Assisted Dying Service must, therefore, notify the Committee prior to cancellation or suspension of registration and must proceed in accordance with any decision of the Committee. All such notification

must have regard to the necessity to protect the identify of practitioners (see para below).

- 318. The register will be confidentially held (i.e., it will not be published) to protect the right to privacy of professionals in a small island jurisdiction. However, access to the register will be available to the Chair of the Committee, as the Jersey Assisted Dying Service holds the register on behalf of the Committee. In addition, information about individual registrants can be shared with relevant organisations, entities and post holders including the Jersey Care Commission (JCC), the Director of Public Health, Chief Nurse, Medical Directors, Chief Pharmacist and Responsible Officers.
- 319. If there are any concerns with the practise of a person on the register, then the Jersey Assisted Dying Service may provide to the person's UK professional regulatory body, and any other relevant authority, including the States of Jersey Police, any registration information that the Jersey Assisted Dying Service deems relevant, whether or not in response to a request from the UK professional regulatory body or other organisation/entity. As the Jersey Assisted Dying Service holds the Register on behalf of the Committee, this must be done with the consent of the Chair of the Committee.
- 320. On adoption of the assisted dying law, during the implementation period, the Committee will work with the Jersey Care Commission and the UK professional regulatory bodies to produce clear guidance on matters to be referred to the UK professional regulatory bodies, this will include but is not restricted to:
  - a. agreed process for referrals to professional regulatory body
  - b. concerns that meet the threshold for referral including concerns:
    - that pose a serious risk to people who use the service
    - where local action can't effectively manage any ongoing risks to people who use the service
    - requiring the UK professional regulatory bodies to take action to protect public confidence in the professions and uphold standards
  - c. notification where a professional is removed from the register due to fitness to practise matters
  - d. In addition to the register not being public, the law will also provide that the names of individual professionals involved in any specific assisted death cannot be made public (see drafting instructions on Offences to follow).

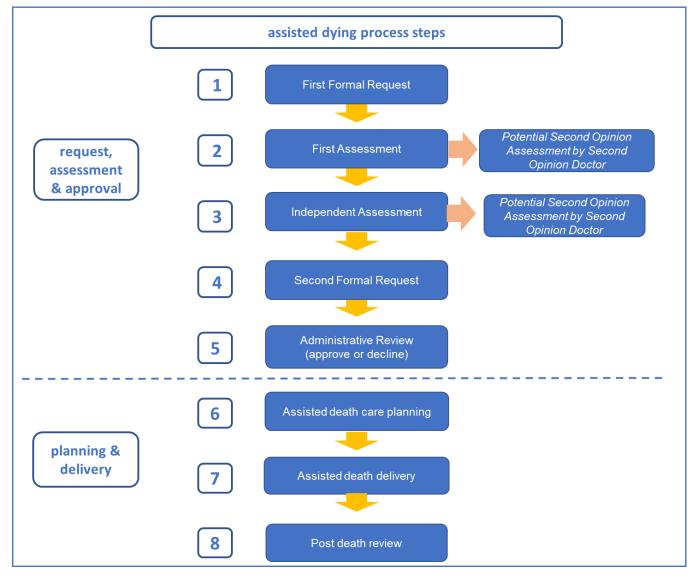
#### Support for professionals

- 321. It is known from other jurisdictions that supporting someone to end their own life has a direct impact on the professionals involved, even though those professionals are committed to supporting people in their choices.
- 322. The law will provide that it is a function of the Committee to make arrangements for the development and provision of systems that support involved professionals and Care Navigators (i.e., those who are directly involved in the assisted death) to process and reflect on the impact and emotions associated with assisting a person to die (for example, counselling / therapeutic de-briefing; peer support groups)
- 323. It is intended that the support systems would also be available to other attending practitioners and carers (i.e., those who are caring for a person who chooses to have an assisted death but not directly involved in the process) but this would be a matter of policy not Law.

# 5. Assisted dying process overview

This section provides an overview of the 8 steps of the assisted dying process.

In this section, elements highlighted in grey, set out policy to be incorporated in the professional guidance, as opposed to covered explicitly by law. The information is included in these instructions for completeness and to help fully articulate the assisted dying process.



Assisted dying process: overview of steps

# Matters that apply to all 8 steps in the process

#### Proceeding through the steps

- 324. The assisted dying process includes 8 distinct steps. Step 1 to Step 5 are part of the request and assessment process; Steps 6 and 7 cover the planning and provision of an assisted death; Step 8 takes place after the assisted death.
- 325. In summary, the law will set out that:
  - a. prior to approval of an assisted death, a person must
    - make a first formal request
    - be assessed as eligible by an assessing doctor at the first assessment and independent assessment
    - make a second formal request for an assisted death
  - b. a Coordinating Doctor may only approve an assisted death following an administrative review to satisfy themselves, at Step 5 that:
    - the Steps 1 to 4 of assisted dying process has been complied with
    - all the relevant forms have been properly completed and the two formal requests are in place; and
    - the person meets all the eligibility criteria.
  - c. an assisted death may only take place if:
    - an assisted death care plan has been agreed and signed by the person (or their signatory) and the Administering Practitioner, and
    - immediately prior to the assisted death, the Final Review has been undertaken by the Administering Practitioner
- 326. The law will set out that the person requesting an assisted death is in control of the pace of the process:
  - a. the steps in the process can only be initiated by the person expressing a wish to proceed to that step, with this wish being recorded:
    - on the first formal request form (wish to transition from Step 1 to Step 2)
    - on a Step Transition form when transitioning from Step 2 to Step 3 / Step 3 to Step 4 / Step 5 to Step 6
    - on the second formal request form (wish to transition from Step 4 to Step 5)
    - during Step 6 on the Assisted Death Care Plan form
    - during Step 7 on the Final Consent and Review form immediately prior to administration / self-administration

b. the person may slow, pause or withdraw their request at any point in the process.

#### Step Transition Forms

- 327. Step Transition Forms are required when a person transitions from Step 2 to 3 / Step 3 to 4 / Step 4 to 5. They serve to record the person's wish to proceed to the next step of the process, except for where the person's wish has already been recorded on:
  - a. the first formal request form
  - b. the second formal request form
  - c. the Assisted Death Care Plan form
  - d. the Final Consent and Review form
- 328. The Committee will develop the Step Transition form, which will include the information/particulars that are:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 329. The Step Transition Form will be in such a format as the Committee decides (i.e., electronic, paper etc.)
- 330. The law will provide that a Step Transition Form:
  - a. must be completed by an Assessing Doctor, and signed and dated by the Assessing Doctor, and signed and dated by the person (or their signatory see section *Signatories*) before the person can commence to the next step
  - b. cannot be completed and signed unless all the requirements of the previous step have been fulfilled (for example, as person cannot transition to Step 3 until all the requirements of Step 2 have been fulfilled)
  - c. must include the Assessing Doctor's determination the person has capacity to make the decision to proceed to the next step in the process
- 331. In signing the Form the person must declare that they wish to proceed to the next step, and that their wish is voluntary (for example, *I declare that I wish to proceed to the next step in the assisted dying process, (name of step). I am making this request to proceed to the next step voluntarily and without coercion)*
- 332. In signing the Form, the Assessing Doctor must confirm that:
  - a. has reviewed the Step Transition Form
  - b. that all the requirements of the proceeding Step have been fulfilled,
  - c. and that they believe, to the best of their knowledge, that the person's wish to proceed to the next step to be a voluntary (for example, *I declare that I have reviewed this Step Transition form, that it is complete and that I am satisfied that the requirements of (name of Step) have been fulfilled and that, to the best of my*

knowledge (name of person)'s wish to proceed to the next step of the assisted dying process (name of step) is freely and voluntarily made"

- 333. The Step Transition Form will provide a record of the following, where applicable:
  - any amendments to information sharing consents (see section below on information sharing consents)
  - any amendments to the person's personal details for example if the person has moved from their home to hospital
  - any emerging conflicts of interest of any involved professionals
- 334. All completed Step Transition Forms will be:
  - a. retained by the Jersey Assisted Dying Service in accordance with the retention schedule and retention arrangements
  - b. subject to examination by the Assisted Death Review Panel as part of the postdeath administrative review (see section *post-death review*)
  - c. available for review, on request, by the Jersey Care Commission as part of their inspection process.

#### Slowing or pausing the process

- 335. After having made a First Formal Request (Step 1), if a person chooses to slow or pause the assisted dying process at any point and indicates this to any involved professionals or the Care Navigator, this and the reason for deciding to slow or pause the process will be recorded in their Assisted Dying Person Record, including any associated wishes for example:
  - a. If choosing to slow the process, the person can, for example, request the Jersey Assisted Dying Service to contact them on a particular date in the future (e.g., in 2 weeks' time)
  - b. If choosing to pause the process the person can, for example, request that the service does not contact them, and they will contact the service if and when they wish to resume the process.
- 336. However, the Assessment Guidance will set out that in determining the settled nature of the person's wish for an assisted death, the time taken to progress through the steps and the reasons for any pauses in the process should be taken into account for example, a reason for pausing the process that would not impact on the settled nature of the person's wish, may be a decision to pause the process to undergo an additional treatment such as an additional round of chemotherapy, but a reason that could impact on the settled nature of the person's wish, could be that the person was unsure that they wanted to proceed with the assisted death.

#### Withdrawal of request

- 337. The law will set out that a person may withdraw their request for an assisted death at any point in the assisted dying process, prior to administration of the assisted dying substance.
- 338. The person may withdraw their request verbally or by any other appropriate means of communication to any involved professional.
- 339. The involved professional must immediately alert the Coordinating Doctor or make arrangements to inform the relevant Coordinating Doctor, if the Coordinating Doctor is not the involved professional who was informed (this will usually be via the Care Navigator). The relevant Coordinating Doctor is the Coordinating Doctor for that person.
- 340. The law will set out that the Coordinating Doctor must then:
  - a. speak with the person to confirm their withdrawal request
  - b. complete and sign a Withdrawal of Request Form
  - c. confirm the withdrawal of request to the person, in writing
  - d. inform other attending practitioners or carers, who were previously informed of the request. [The appropriate Information Sharing Consents must be in place]
  - e. inform family members, friends and other third parties of the subsequent withdrawal, where they have been involved in the process to date. [The appropriate Information Sharing Consents must be in place].
  - f. The assisted dying process stops as soon as the person withdraws their request.
- 341. The Committee will develop the Withdrawal of Request Form which must include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 342. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.)
- 343. It is understood that the person may tell other attending practitioners or carers or a family member or the Care Navigator or other member of the Jersey Assisted Dying service who is not an involved professional, of their wish to withdraw their request. To help assist in this eventuality, the Guidance for Families and Carers, published by the Committee will set out how to notify the Jersey Assisted Dying Service of the wish to withdraw, but there will not be a legal requirement to do so.

- 344. The Guidance for Families and Carers is non-professional guidance.
- 345. The law will set out that completed withdrawal of request form must be retained by the Jersey Assisted Dying Service in line with the Assisted Dying retention schedule and retention arrangements. The assisted dying service must report to the JCC, on an annual basis:
  - a. the numbers of withdrawal of requests
  - b. the stage of the application/delivery process when the request was withdrawn.

A person who has withdrawn their request may, at any later date, start the request processes again from the beginning (i.e., they will need to go back to Step 1 and make a first formal request) but the *Assessment Guidance* will state that, the fact that they had previously withdrawn a request, must be considered by the assessing doctors when determining whether their future wish for an assisted death is clear and settled.

#### Refusal of request

- 346. The law will set out that the Coordinating Doctor may refuse the person's request for an assisted death, at the following points in the process:
  - a. end of first formal request
  - b. end of first assessment
  - c. end of independent assessment
  - d. end of second formal request
  - e. end of administrative review.
- 347. At the end of the first assessment, independent assessment and the administrative review, the Coordinating Doctor, may only refuse the person's request if they do not meet one or more of the eligibility criteria.
- 348. At the end of the first formal request, the Coordinating Doctor may only refuse the person's request if they are of the opinion that their first formal request is not clear and unambiguous.
- 349. At the end of the second formal request the Coordinating Doctor may only refuse the person's request if they are of the opinion that the person's request, is not voluntary, clear, settled and informed (the person will not be making a second formal request if they have not been found to meet all the other eligibility criteria during the first assessment and independent assessment).
- 350. In making a refusal of request, the Coordinating Doctor must document the reasons for refusal. They will do so on the relevant form (i.e., the form that corresponds to the step in the process in which the refusal determination was made).

- 351. Refusal of Request signifies the end of the assisted dying process for the person (i.e., the person may not proceed to the next step). The person may, however:
  - a. make an appeal, if the refusal is on grounds that are eligible for appeal
  - b. make a second opinion assessment request following the first or independent assessment, but only if the refusal is on grounds other than the grounds of age or residency.
- 352. The Committee will develop the Refusal of Request Form which will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 353. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.)

#### Minimum timeframes

- 354. The law will set out the minimum timeframe for the assisted dying process to be undertaken will be 14 days – subject to the exception described below. Day 1 will be the date on which the person (or their signatory) signs the first formal request form (Step 1), Day 14 will be the date the assisted dying substance is administered (Step 7).
- 355. The statutory minimum timeframe will help to ensure the person has had time to reflect on their assisted dying request i.e., help safeguard against hasty decision making or fluctuating wishes for an assisted death. 14-day minimum timeframe allows sufficient time for all assessments to be completed, and time for the assessing doctors to be confident that the request for an assisted death is enduring, whilst not unduly extending any suffering and uncertainty for the person. This is in line with legislation in the US, Spain, Austria and the proposals set in the Isle of Man Assisted Dying Bill and Scottish consultation proposals.

#### Exception to minimum timeframe

- 356. The law will provide that the minimum timeframe may be disapplied by the Coordinating Doctor at the administrative review stage if in the opinion of both the Coordinating Doctor and the Independent Assessment Doctor the person has 14 days or less to live – from the point at which the assessing doctor makes the determination/ signs the assessment form.
- 357. It is generally the case that 14 days or less life expectancy will be determined by the Coordinating Doctor during the first Assessment and the Independent Assessment

Doctor during Independent Assessment ("initial determination of life expectancy") but it may be that there is a rapid decline in the person's condition – and hence their life expectancy – after the first assessment and / or after independent assessment. The law should therefore allow that:

- a. the Coordinating Doctor may make a revised life expectancy determination at any point after the first assessment, and
- b. the Independent Assessment Doctor may make a revised life expectancy determination outside of the Independent Assessment, if the conditions below are met.
- c. if the Independent Assessment Doctor is not available to make a revised life expectancy determination, another registered Assisted dying practitioner Assessing Doctor may make a revised life expectancy determination in their place, again if the conditions below are met
- 358. The conditions are:
  - a. it becomes apparent that the person's condition has deteriorated, and
  - b. the person confirms they wish for revised life expectancy determination to be made whether by just the Coordinating Doctor (if the Coordinating Doctor's initial determination was of life expectancy of more than 14 days but the Independent Assessment Doctor's initial determination was for 14 days or less due to deterioration between the two assessments) or both the Coordinating Doctor and Independent Assessment Doctor (or alternative assessing doctor) (if period of deterioration is after both assessments)
- 359. Where both assessing doctors have determined life expectancy of 14 days or less, the Coordinating Doctor will disapply the minimum timeframe at administrative review stage and will confirm their decision to disapply the timeframes on the administrative review stage form.
- 360. The Coordinating Doctor may disapply the timeframe without reverting to the Independent Assessment Doctor, if the Independent Assessment Doctor had recorded on the Independent Assessment Form a life expectancy of 14 days or less BUT if the Independent Assessment Doctor made a revised determination after completion of the Independent Assessment Form, the Independent Assessment Doctor must confirm this decision on the Administrative Review (approve or refuse) form. Or if an alternative Assessing Doctor has made a revised life expectancy determination, in place of the Independent Assessment Doctor, they must confirm this on the Administrative Review (approve or refuse) Form.
- 361. Where the 14 day minimum timeframe has been disapplied by the Coordinating Doctor, the 2 working days requirement from final approval (Step 5 to the administration of the substance [see instructions on Appeals, to follow]) is also automatically disapplied BUT all other assessment and approval processes must be undertaken as set out in the law and guidance (including, for example, undertaking any

supporting assessments where required for and assessing doctor to make a determination of eligibility).

- 362. Some other jurisdictions, including Western Australia, similarly allow for minimum timeframes to be disapplied in the event that a person is expected to die within that timeframe.
- 363. There will be no maximum timeframe set out in law on the grounds that:
  - a. the person must be able to dictate the pace at which they move through the process (beyond the minimum timeframes); and
  - b. in some cases, there will be a requirement to involve specialist professionals and access to those professionals may be limited for example if the assessing doctor determines a supporting assessment is required by a psychiatrist, there may not be any on-island professionals willing or available to undertake the assessment.
- 364. Note: Whilst there are no maximum timeframes in law, the Committee is required to make arrangements for the development of the Jersey Assisted Dying Service service standards, and is required to publish those services standards. Any timeframes set out in those standards are target timeframes for the operation of the Service they are not to be construed as the timeframes in which a person must progress through the assisted dying process.

#### Assisted dying forms

- 365. At each Step in the process there will be forms to be completed by the assessing doctors, Administering Practitioner and / or others.
- 366. The Committee will develop and consult on all forms. The forms will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 367. The forms will be in such a format as the Committee decides (i.e., electronic, paper etc.)
- 368. All completed forms will:
  - a. form part of the person's Assisted Dying Person Record
  - b. be retained by the Jersey Assisted Dying Service in accordance with the retention schedule and retention arrangements

- c. be subject to examination by the Assisted Death Review Panel as part of the postdeath administrative review (see section *post-death review*)
- d. be available for review, on request, by the Jersey Care Commission as part of their inspection process.

#### **Signatories**

- 369. The law will provide that if the person is physically unable to sign a form that requires the person's signature, the person may instruct someone sign on their behalf but <u>only</u> if they are physically unable to sign themselves (i.e., there are no other circumstances a form can be signed by another person).
- 370. The person signing on their behalf ("the signatory") may be any person aged 18 or over, who is not:
  - a. the Coordinating Doctor
  - b. any other involved professional
  - c. the person who acts as witness to the signing of Second Formal Request form
- 371. It can be a friend or family member of the person.
- 372. The Signatory must be instructed to sign the form by the person in front of the Coordinating Doctor, and must sign the form in the presence of both Coordinating Doctor and the person. The Coordinating Doctor must then immediately sign the form in the presence of both signatory and the person.
- 373. All Forms will need to provide for recording the details of any signatory. These details include the signatory's name; confirmation that they are over 18 years old; contact details, relationship to the person.
- 374. The person may have more than one signatory throughout the assisted dying process - the same person may be the signatory for all forms signed on behalf of the person during the process or a different person may act as signatory for some or all forms in the process.
- 375. Where a signatory has been instructed by the person to sign a form on their behalf, the form will be recognised as one that has been signed by the person.

#### Assisted Dying Person Record and Guidance

376. The law will set out that it is a function of the Committee to make arrangements for the development of the system for holding Assisted Dying Person Records and for the development of the Assisted Dying Person Record Guidance. The Committee must

approve the arrangements for the system and the Guidance, and make available to relevant persons.

- 377. The Assisted Dying Person Record system holds a single assisted dying record for each person who makes a first formal request for an assisted death, regardless of the outcome of the request. Each Assisted Dying Person Record provides a single point of information and will hold:
  - a. personal details for each person making a first formal request
  - b. all the completed assisted dying forms for that person
  - c. all documents, correspondence, reports or other information that are relevant to that person's request (including assessment of request, approval, planning and delivery of an assisted death, post assisted death)
- 378. The Law should not be prescriptive as to whether:
  - a. the Assisted Dying Person Record is an electronic or paper record (or a combination of both)
  - b. is held separately to a person's hospital record.
- 379. The Assisted Dying Person Record Guidance will set out matters related to:
  - a. access to Assisted Dying Person Record (who may access what elements of the Record and for what purpose; any processes associated with provision of permission to access)
  - b. how the records should be held and catalogued to support inspection and audit purposes. For example, the Records must be held in such as manner as to readily allow for:
    - i. oversight of the assisted practitioners' current and past case loads, and their associated decision making in across assisted dying requests
    - ii. 'profiling' of people who request an assisted death and / or have an assisted death
- 380. The law will set out that the Assisted Dying Person Records will be:
  - a. made available on request to the Jersey Care Commission as part of their inspection processes, and
  - b. provided to the Assisted Dying Review Panel as part of the post-death administrative review (See section *post-death review*).

<u>Communication support and advocacy (referred to as *communications support* in these instructions)</u>

- 381. When a person is referred to the Jersey Assisted Dying Service, the Care Navigator will work to determine whether the person needs communications support in order to make a first formal request.
- 382. The law will set out that during the First Assessment, the Coordinating Doctor must assess the person in order to determine:
  - a. the extent to which the person is able to communicate matters related to their assisted dying request and / or receive and understand information provided to them
  - b. the extent to which they would be able to communicate matters and understand information related to their assisted dying request if provided communications support, and
  - c. the type and degree of support required.
- 383. The purpose of the assessment is to enable the Coordinating Doctor to be satisfied that the person can (with or without communication support) communicate matters related to their assisted dying request to an extent which allows the Coordinating Doctor and other assessing doctors to determine the person's eligibility.
- 384. For the purposes of these instructions 'types of communications support' may include:
  - a. foreign language / British Sign Language interpreters this may involve in-person or remote interpreting support via video link
  - communication support this could involve technology such as speech to text software, or in-person support from a professional such as a speech and language therapist
  - c. independent advocacy this involves support for the person to get the information they need to make choices about their current care and treatment options and request for assisted dying. And to support the person to put their choices across to professionals during the assisted dying process.<sup>51</sup>
- 385. This list above is not an exhaustive list. The Coordinating Doctor may determine that other forms of communications support may be appropriate.
- 386. For the purposes of these instructions 'degree of communications support' means how often and when the person needs that support (for example, they may need an independent advocate to be present in meetings with assessing doctors only, or meetings with assessing doctors and supporting assessment / opinion professionals)
- 387. In making the determination as to whether communications support is required the Coordinating Doctor:

<sup>&</sup>lt;sup>51</sup> Someone to speak up for you (advocate) - Social care and support guide - NHS (www.nhs.uk)

- a. must have regard to the following matters:
  - the Interpreting, Communication, Support and Advocacy Guidance (see below)
  - availability of the necessary resources or expertise
- b. may engage relevant members of the Assisted Dying Service MDT or any other relevant person who the Coordinating Doctor determines can provide a supporting assessment / opinions (this could include, for example, a social worker or a member of the person's family).
- 388. In the event that the Coordinating Doctor determines communication support is required, the Coordinating Doctor must make arrangements for the provision of that support. The support may be provided via a third party (e.g.: a remote interpretation service or worker for a mental health advocacy charity, another attending practitioners and carers) or a connected party (e.g.: a friend / relative of the person / someone who them in a personal capacity).
- 389. If the Coordinating Doctor cannot be satisfied that the person can (with or without communication support) communicate matters related to their assisted dying request to an extent which allows determination the person's eligibility for an assisted death, the Coordinating Doctor will need to conclude that the person is not eligible.
- 390. The law will also provide that:
  - a. a Second Opinion Doctor who is undertaking a full assessment (whether a full first assessment or a full independent assessment) and
  - b. the Independent Assessment Doctor during the Independent Assessment, and
  - c. the Administering Practitioner during the Assisted Death Care Planning stage and delivery stage

must also satisfy themselves that the person is able communicate matters related to their assisted dying request (either with or without any communication support that may already be in place)

- 391. If they are not satisfied, the Second Opinion Doctor / Independent Assessment Doctor / Administering Practitioner must:
  - a. determine the extent to which the person would be able to communicate such matters if provided communications support, and
  - b. determine the type and degree of support required, and
  - c. make arrangements for the provision of that support, having regard to the same matters as the Coordinating Doctor

- 392. If the Second Opinion Doctor / Independent Assessment Doctor cannot be satisfied that the person can (with or without communication support / additional communications support) communicate matters related to their assisted dying request to an extent which allows determination the person's eligibility for an assisted death, the Second Opinion Doctor / Independent Assessment Doctor will need to conclude that the person is not eligible.
- 393. The Committee must make arrangement for the development of Interpreting, Communication, Support and Advocacy Guidance, which it must approve and make available to relevant persons. In developing it, the Committee must consult with the entities or persons that the Committee deems are relevant to consult.
- 394. The Communication, Support and Advocacy Guidance will specify matters related to:
  - a. the process for arranging for interpretation, communication or advocacy support, which will be the responsibility of the Jersey Assisted Dying service
  - b. that a person with a disability, where that disability affects their ability to communicate, can use their preferred means of communication (e.g. a communication aid, writing or gestures) during the assessment process
  - c. where remote support / interpreting is appropriate and which stages of the process require in-person support
  - support available to the professional providing the communication support, if required
  - e. additional considerations for the assessment process, for example:
    - the assessing doctor should allow for additional time for the consultation, if support or advocacy is required
    - potential requirement for pre-brief and debrief with the interpreter or communication support, to allow for a shared understanding of the process and purpose of the session and to discuss any sensitive matters.

Providers of communications support

- 395. The law will set out that any person who provides communication support during any part of the assisted dying process will need to sign a Specific Person Declaration of Interest Form. (See Section on *Specific Person Declaration of Interest Form*)
- 396. Note; where the person providing communications support is a connected party (e.g.: a friend / relative of the person / someone who them in a personal capacity), they will not be asked to declare if they are a known or potential beneficiary of the person's Will

OR may otherwise benefit financially or in any other material way from the death of this person, due to any associated distress.

- 397. The law will also require:
  - a. all relevant forms to capture information about the involvement of a communications support provider in that stage of the process (For example, if a communications support provider provided support during the First Assessment a description of their involvement must be captured on the First Assessment Report form)
  - b. the provider to sign and date the relevant form, confirming that the description of their involvement is accurate.

#### On-island assisted dying appointments

- 398. An assisted dying appointment is for the purposes of these instructions a meeting between the person who has requested / has stated they want to request an assisted death and an assessing doctor or administering practitioner.
- 399. The law will provide that all assisted dying appointments (whether in-person or remote) must be conducted on-island. This includes:
  - a. any meetings between the person and an assessing doctor which related to the person's request for an assisted death
  - b. any meetings where the person (their signatory) is required to sign one of the forms prescribed in this law
  - c. any meetings between the person and an Administering Practitioner during the assisted death care planning phase
  - d. the provision of the assisted death, including Final Review and administration of the substance
- 400. If the assisted dying practitioner is a non-Jersey based professional, they must travel to Jersey to undertake the appointment.
- 401. This is to ensure there are no difficulties associated with a practitioner being involved in the assisted dying process when physically present in a jurisdiction where assisted dying is not legal. Currently, assisted dying is not permitted in the UK and it is an offence to actively encourage or assist someone with ending their life.
- 402. The law will not stipulate that assisted dying appointments need to be in person but, the Assessment Guidance will set out that:

- a. initial and in-depth consultation and discussion must be in-person appointments (they may, for example, take place in the person's home, place of care or elsewhere such as the Jersey General Hospital) and
- that generally all assisted dying appointments should be in-person, but there may be certain circumstances where follow-up appointments can be carried out remotely i.e. over the phone, via video link or online (for example, clarification of matters already discussed)

#### Information Sharing Consents

- 403. For the purpose of these instructions, *information sharing consents* means the consent of the person to provide and exchange information with other parties (i.e. to tell another party something, to ask another party something, or receive information from another party). The information can be shared in any appropriate manner or format (i.e. in writing, verbally, pictorially)
- 404. The person who is providing the consent may be a person who has requested an assisted death / has indicated their intention to request an assisted death / has sought information about assisted dying.
- 405. Other parties with whom information may be exchanged include:
  - Family / friends
  - Persons engaged by the Jersey Assisted Dying Service (e.g.: other assisted dying practitioners / Care Navigators)
  - other attending practitioners and carers
  - providers of supporting assessments / opinions
  - the JCC / the Committee / the post death review panel
  - any other person or entity the person provides consent to share information with, or requests information is shared with
  - other Government Departments.
- 406. Other parties may be named professionals (for example the person's Consultant or GP) or unnamed professionals, for example the care staff at their residential home or on a hospital ward
- 407. The information that can be shared includes matters related to the person's:
  - assisted dying request
  - their eligibility / potential eligibility (i.e., any information that may be required to determine their eligibility)
  - their condition or illness
  - their treatment for that condition
- 408. The information can include:

- a. existing relevant records (person's medical records; social work and social care records, multi-agency safeguarding hub; CLS records relating to residency / period of residency)
- b. information that is shared, post-death / post-withdrawal of request / postdetermination of request for audit and inspection purposes
- c. information from any relevant Government of Jersey department that enables the Jersey Assisted Dying Service to confirm residential status and age (as two of the assisted dying eligibility criteria). Note: this would not include disclosure of the person's assisted dying request as it is not relevant to the information being sought.
- 409. The person must be informed, as part of the first formal request of the potential implications of:
  - not providing consents i.e. the Coordinating Doctor or other assessing doctors may be unable to confirm eligibility for an assisted death (as they may, for example, be unable to determine the voluntary, clear and settled nature of the wish without third party input or unable to determine residency) and
  - providing consents (i.e., people will know about the request and may attempt intervention if they are not supportive)
- 410. It may be necessary at any point during the assisted dying process for the Coordinating Doctor or any other assisted dying practitioners (for example a member of the MDT team) to seek additional consents / make arrangements to seek additional consents from the person (for example by asking the Care Navigator to request the additional consents).
- 411. All requests for additional consents must be noted on the person's Assisted Dying Person Record including whether the person does or does not provide that consent, and who the person provides the consent to (i.e., Coordinating Doctor only and / or others).
- 412. The Committee will develop the Information Sharing Consents Form which must include the information/particulars that is:
  - e. provided for in the law
  - f. prescribed by Order of the Minister
  - g. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 413. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.
- 414. The law will provide the Information Sharing Consents form must be signed by the person (their signatory) and an assessing doctor or the Administering Practitioner.

#### Involvement family / friends / other attending practitioners and carers

- 415. The Assessment Guidance will set out that the person requesting an assisted death will be encouraged by the Assessing Doctors / Administering Practitioner to involve family / friends / other attending practitioners and carers in the process (unless there are compelling reasons not to do so). However, the person has a right to privacy and will not be required to inform family / friends / other attending practitioners and carers about their request, assessment, or approval for assisted dying. Nor will they be required to provide the Information Sharing Consents what would allow for the Jersey Assisted Dying Service to contact or engage with family / friends / other attending practitioners and carers.
- 416. The Assessment Guidance will also set out that where person does provide Information Sharing Consents enabling family / friends / other attending practitioners and carers to be involved in the process, the Care Navigator and Coordinating Doctor will support family / friends / other attending practitioners and carers through the process, as required. This may involve making themselves available for discussion about the process and answering any questions. It may also involve signposting them to other support and wellbeing services provided by HCS or other providers.
- 417. The law will provide that:
  - a. the Coordinating Doctor must, as part of the First Formal Request, ask the person to provide Information Sharing Consents allowing the Assisted Dying Service to share information with family / friends / other attending practitioners
  - b. the person may decline to provide the necessary Information Sharing Consents
  - c. if the person declines to provide Information Sharing Consents, the Coordinating Doctor must inform the person that this may have an impact on the ability of Assessing Doctors to determine if the person meets the eligible criteria. For example, without speaking to family / friends, the assessing doctor may not be able to determine if the person is requesting assisted dying voluntarily and without coercion.
- 418. For clarity, if a person who is family / friends / other attending practitioners and carers does not support the person's request for assisted dying, this will not affect the assessment of the person's eligibility (i.e., a person would not be ineligible on the basis that their family do not support their wishes), unless the family / friends / other attending practitioners and carers provides information or insight that suggests the person does not meet the eligibility criteria, and the Coordinating Doctor determines that information or insight is correct (for example, they believe they are not making the request voluntarily)
- 419. The Committee will publish Guidance for Families and Carers (non-professional guidance), which will include easy to understand information on:

- a. the family / friends / other attending practitioners and carers role / potential role in the process
- b. the assisted dying process
- c. the assisted dying appeals process
- d. the assisted dying complaints and concerns policy
- e. how to support a family member who is requesting assisted dying
- f. how to access support services
- g. how to notify the Jersey Assisted Dying Service, if the person indicates to the family / friends / other attending practitioners and carers that they wish to withdraw their assisted dying request

#### Declaration of Interest (Registration Declaration and Specific Person Declaration)

#### Registration declaration

- 420. The law will set out that all assisted dying practitioners and ADRMPs must, on registration with the Jersey Assisted Dying Service complete a Declaration of Interest form.
- 421. The Committee will develop the Declaration of Interest form, which will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 422. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.)
- 423. It is envisaged that the Minister will, by Order, determine that the form must provide for a declaration of the following:
  - a. directorships, partnerships or registerable share holdings
  - b. membership of governing bodies or other public bodies
  - c. interests related to assisted dying or end-of-life care including those related to previous current employment or consultancy

- d. interests of close family members
- e. other matters which may be perceived to create a conflict
- 424. This information provided via the Declaration of Interest form will be held on the Jersey Assisted Dying Service Register. Assisted dying practitioners will be required to review their declaration of interest on an annual basis, alongside their annual renewal of registration. However, an assisted dying practitioner or ADRMP may choose to update their registration declaration at any point, should their declaration change during the course of the year.

#### Specific Person Declaration

- 425. In addition, the law will provide that the following must compete a Specific Person Declaration of Interest Form at the point at which they have agreed to be involved in any part of the assisted dying process pertaining to a specific individual:
  - a. Any involved professionals (except Pharmacy Professionals)
  - b. any person providing a professional assessment / opinion (this does not include anyone providing a *connected person opinion*)
  - c. any person who provides communications support, unless they are a connected person
  - d. the Care Navigator
  - e. ADRMP
- 426. The Form will be in such a form as the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 427. The persons required to complete the form must do so each time they are asked to be involved in the assisted dying process for a specific individual person.
- 428. It is envisaged that the Minister will, by Order, determine that the form must provide for that the persons must declare the following. If they:
  - a. are a relative of the person, including a description of their relation to the person (this includes whether they are partner i.e., living in a relationship which is akin to a marriage or a civil partnership)
  - b. are a friend or associate of the person, including a description of the capacity in which they know them

- c. are a known beneficiary of the person's Will, or believe they may be a potential beneficiary
- d. may otherwise benefit financially or in any other material way from the death of this person
- e. are the owner, provider or manager of a health or care facility where the person is being treated or lives
- f. are directly involved in providing health or care to the person and if so, in what capacity or role
- g. have any other interests or potential conflicts.
- 429. In addition, it is envisaged that the Order will provide that where the person (who is not a connected party) is a provider of communications support, they must provide details of their professional qualifications, role and the organisation they currently work for, and with regard to interpreters whether or not they hold a nationally recognised interpretation qualification and are registered with the NRPSI (National Register of Public Service Interpreters) or equivalent body
- 430. Note: as stated above, where a person is providing communication support as an independent third party (but not a connected party), they will also be required to declare any interests.

#### Determining conflicts at point of registration

- 431. Where an actual conflict / potential conflict of interest is declared on a completed Registration Declaration, the Form will be reviewed by a person who holds the post of Medical Director (or equivalent), or by a person whom the Medical Director determines is an appropriate person to make such as assessment (the Reviewing Officer).
- 432. The Reviewing Officer will then determine if, any interests declared represent a degree of conflict which, in is the opinion of the Reviewing Officer, means that professional should not be registered as an assisted dying practitioner/ ADRMP.
- 433. Further detail on declaring interests and determination of any actual or potential conflicts of interest will be outlined in the Assisted Dying Declaration of Interests Policy, to be developed and published by the Committee.

#### Determining conflicts at point

434. Where a conflict / potential conflict is declared on a Specific Person Declaration of Interest Form, the Form will be reviewed by the Reviewing Officer.

- 435. The Reviewing Officer will determine if:
  - a. any of the interests declared mean the person is prohibited by law from being involved in the assisted dying process for the specific person, or
  - b. represent a degree of conflict which, in the opinion of the Reviewing Officer, means that professional should not be involved in the assisted dying process for the specific person.
- 436. The law should provide that people are prohibited if they are:
  - a. are a relative of the person to a close degree of connection
  - b. are a known beneficiary of the person's Will, or believe they may be a potential beneficiary
  - c. may otherwise benefit financially or in any other material way from the death of this person
- 437. For clarity, a close degree of connection is intended to include:
  - a. Husband/wife/spouse/partner (i.e., in a relationship which is akin to a marriage or a civil partnership).
  - b. Child/Parent (including, adoptive child and former adoptive child)
  - c. Grandchild/grandparent (including adoptive grandchild and former adoptive grandchild)
  - d. Sibling
  - e. First cousin
  - f. Parent's sibling i.e. aunt/uncle
  - g. Sibling's child i.e. nephew/niece
- 438. The process for making a determination of conflicts of interest will be outlined in the Assisted Dying Declaration of Interests Policy.

# 6. Assisted dying process – request, assessment and approval

This section details how requests, assessments and approvals for assisted dying will operate (Steps 1 to 5 of the proposed assisted dying process). These are the steps to ensure that only people who meet the eligibility criteria set out in law are assessed and approved for an assisted death.

This section also details activity prior to the commencement of formal process steps, for example, referrals and requesting information (known as "pre-process steps").

In this section, elements highlighted in grey, set out policy that will be reflected in guidance only, not covered explicitly by law, but is included here for completeness to fully articulate the assisted dying process and to provide context for these drafting instructions.

## **Pre-process steps: information and referral to the Jersey Assisted Dying Service**

439. As set out in *Functions of the Jersey Assisted Dying Service*, the Service will develop and publish information about assisted dying in Jersey and provide that information to any person requesting it.

#### General enquiry

- 440. A person who wants more information about the Assisted Dying in Jersey may make direct contact with the Service (via phone, email or an online form).
- 441. The basic details of all general enquiries will be logged by the Jersey Assisted Dying Service for annual reporting purposes (i.e., number and type of inquiries) but the names of people making inquiries will not be recorded other than where the person has specifically provided their name for the purpose of ongoing contact and discussion. This is to ensure that people feel able to make confidential private initial inquiries.

#### <u>Referral</u>

442. The law will set out that a person who is considering making a request for an assisted death may directly contact the Service about requesting an assisted death (this is called self-referral) or may be referred by another professional, for example, their GP (this is called professional referral). Professional referral is, as a matter of practice,

required for access to many other services, but the law should specifically provide that self-referral must be permissible for the Jersey Assisted Dying Service.

#### Self-referral

- 443. When a person self-refers, initial contact will be with a Care Navigator. A person may wish to have several informal discussions with the Care Navigator over a period of time before deciding whether:
  - to meet with a Coordinating Doctor in order that they may then make a first formal request for assisted dying
  - not to make a first formal request.
- 444. The law will provide that if a person tells the Care Navigator they want to make a first formal request for assisted dying / would like to meet with an Coordinating Doctor to consider matter related to making a first formal request, the Care Navigator will:
  - a. set up an Assisted Dying Person Record for that person:
  - b. record in the Record, that the person has self-referred (or if it's a professional referral)
  - c. arrange for the person to meet with a Coordinating Doctor so that they can begin Step 1: first formal request
  - d. formally record in the record that a meeting has been arranged with a Coordinating Doctor
  - e. establish if the person will require any communication support during the first formal request meeting/s with the Coordinating Doctor, record any requirement in their assisted dying person record and arrange for the required support to be in place.

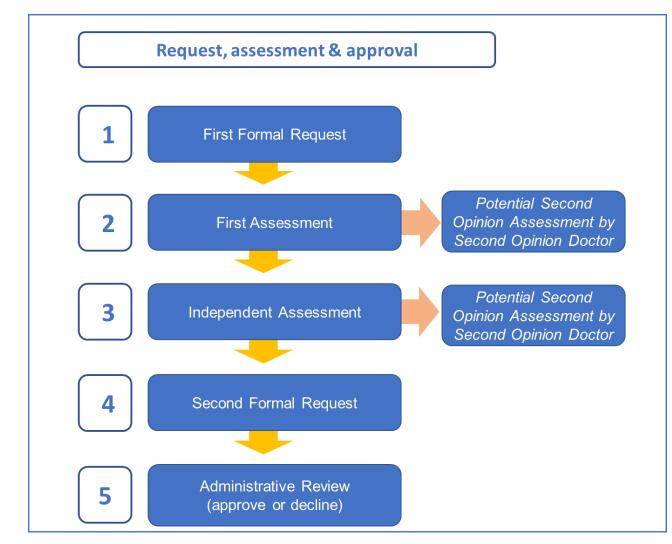
Note: during the first formal request meeting the Coordinating Doctor will then consider whether additional ongoing communication support is needed during the first formal request process, ahead of to a full assessment of communication support needs during the first assessment.

- 445. The Care Navigator will complete an Initial Enquiry Form recording the person's name and contact details, that the person has indicated they want make a first formal request, the date of the meeting with the Coordinating Doctor.
- 446. The Initial Enquiry form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult

447. The Care Navigator will only complete an Initial Enquiry form if the person states they want to make a first formal request / would like to meet with a Coordinating Doctor to consider matter related to making a first formal request

#### Professional referral

- 448. As per *Right to Refuse* section, the Right to Refuse & Conscientious Objection Guidance will set out that a health and care professional may refuse to refer the person to the Jersey Assisted Dying Service, but if they do so, they must inform the person of how to contact the Service so that the person may make a self-referral, or make arrangements for another professional to make a referral (see section on *Right to refuse to participate in the assisted dying process*).
- 449. If a health and care professional refers a person to the Jersey Assisted Dying Service, the law will provide that the Care Navigator must record:
  - The date the referral is received
  - The name of the referrer
  - A description of the referrer's professional relationship to person e.g., their GP
  - Any other relevant information, as determined by the Committee
  - a. contact the person to establish if they:
    - want information about assisted dying; in which case the Care Navigator will provide that information
    - wish to make a first formal request
- 450. The law will provide that if a person tells the Care Navigator they want to make a first formal request for assisted dying, the Care Navigator will undertake the steps as described in paragraphs 444 & 445 above. This includes completion of an Initial Enquiry Form.



Process steps for request, assessment and approval for assisted dying

## Step 1: First formal request

#### First Formal Request meetings and form

- 451. Step 1: first formal request 'starts' the assisted dying process and signifies a shift from informal consideration of assisted dying to formal intent of a person to initiate the assisted death assessment process.
- 452. Step 1 is a process which involves the person:
  - a. discussing their prognosis, treatment options and assisted dying with the Coordinating Doctor and culminates in the person determining if they want to make a first formal request for an assisted death. This may require one first formal request meeting between the person and the Coordinating Doctor, or multiple meetings over a protracted period of time

b. making or not making a first formal request for an assisted death (note: if the person decides they want to make a first formal request this is not, for the purposes of the law consider to be an informed decision for which they need consent. This is because, at this stage they will not necessarily have all the information they need to make an informed decision)

#### Does not make a first formal request

- 453. If the person does not inform the Coordinating Doctor if they want to make a first formal request, the Jersey Assisted Dying Service will not take any action.
- 454. If the person informs the Coordinating Doctor they have decided not to make a first formal request, the process will stop and this will be noted by the Coordinating Doctor on the First Formal Request form. This will not be considered a Withdrawal of Request, as the person will not have made a first formal request.

# Makes a first formal request

- 455. The law will provide that if the person decides to make a first formal request, that request must be clear and unambiguous.
- 456. The person must make the first formal request by signing (or instructing their signatory to sign) the First Formal Request form. That form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 457. The law will provide that the First Formal Request Form must record the person's consent to proceed to Step 2 (First Assessment).
- 458. At the time of the person making the First Formal Request, the law will require the Coordinating Doctor to provide the person with information about the assisted dying process, as approved and published by the Committee. *The Approved Information* is to include:
  - a. details of the assisted dying process, including:
    - i. the request and assessment process, including eligibility criteria
    - ii. approval of an assisted death
    - iii. assisted death care planning
    - iv. the assisted death and administration of the assisted dying substance

- b. details of the appeals process
- c. signpost the person and their connected person to counselling and support services
- d. details of the Assisted Dying Complaints and Concerns policy
- e. information about personal administrative matters, including consideration of whether an assisted death may impact the person's life insurance arrangements and other financial affairs
- 459. For the purposes of clarity, the *Approved Information* will be set out in a written document. The Coordinating Doctor may provide that written document to the person (depending on the Coordinating Doctor's assessment of the person's ability to read, assimilate and understand the written document) but, regardless of whether the Coordinating Doctor does or does not provide the written document, they must communicate all the information to the person (either with or without communication support) and must be satisfied that the person has understood the information.
- 460. If the First Formal Request is accepted by the Coordinating Doctor, The First Formal Request form must be signed and dated by the Coordinating Doctor, and the person (their signatory), in the presence of each other. NOTE: there is no requirement for the signing of the First Formal Request Form to be witnessed.
- 461. The Coordinating Doctor may refuse a person's first formal request if during the course of the first formal request meeting/s the Coordinating Doctor reasonably believes the person's request is not clear and unambiguous. They cannot refuse that request, as this stage, on other matters of eligibility as these are still to be determined
- 462. If the Coordinating Doctor refuses the person's request, they must complete a Refusal of Request form and the process will stop. [Note: the Coordinating Doctor is actually refusing a request that the person has not yet formally made as the first formal request process has not yet been completed but the Refusal of Request form is nevertheless completed as the person did wish to make the request, and completion of the form provides a mechanism for appeal and review by the Assisted Dying Review Panel]
- 463. If the process is stopped at this point in the process, it cannot be restarted (i.e., there is no appeal or second opinion request process), but it can start again if the person makes a new first formal request.

# Repeat first requests

464. Where a person has requested an assisted death but it has been determined that the person is not eligible for an assisted death (regardless of when in the assisted dying process they were found ineligible), the law should provide that the person make a new first formal request where the person believes that a change in their circumstances means they are now potentially eligible for an assisted death.

- 465. For the purpose of clarity, the person is making new first formal request as distinct from a repeat first formal request i.e., they are not appealing a previous decision to find them ineligible (i.e., the purpose of the new request is to say "I am making a new request because my circumstances have changed, not to say "please review your previous decision as you were wrong").
- 466. Where a new first request is made a Coordinating Doctor can refuse to accept this new first formal request (even where the Coordinating Doctor is satisfied as to the nature of the wish) if Coordinating Doctor determines that the previous reasons for non-eligibility still exist.
- 467. The Coordinating Doctor may make this decision following a review of the:
  - a. person's previous assisted dying request/s and assessment/s, and
  - b. any subsequent medical notes or care record.
- 468. For the purposes of clarity, the law should not limit the number of First Formal Requests a person may make.
- 469. Note: where the Doctor believes that there may be new reasons for non-eligibility as opposed to previous reasons for non-eligibility (for example, the Doctor believes the person may no longer have capacity) the Doctor should not refuse the new first formal request. They should instead, proceed to first formal assessment, and consider / determine the potential new reasons for non-eligibility as part of the first formal request process.

#### Note: Two separate requests

The assisted dying process requires a first formal request at Step 1 and a second formal request at Step 4. The first formal request signifies the shift from informal consideration of assisted dying to formal intent of a person to initiate the assisted death assessment process. It is not expected that, as this stage in the process, that the request will be fully informed, but it must be clear and unambiguous.

This is different from the second formal request which must be voluntary, clear, settled and informed. The second request signifies the person's intent to proceed to having an assisted death, following the assessment process and having been fully informed of the assisted dying process.

Together, both requests signify the clear, settled nature of the person's wish for an assisted death.

- 470. Detailed Assessment Guidance will be developed by the Committee. It will set out matters related to whole assessment process, including the first assessment
- 471. Before the first assessment can commence the person must have made first formal request which must have been accepted by the Coordinating Doctor. The first formal request form will record the person's wish and consent to proceed to Step 2.
- 472. The first assessment may take place immediately after the first formal request or at a later date.
- 473. The law will set out that a first assessment must be undertaken by the Coordinating Doctor.
- 474. The purpose of the first assessment is for the Coordinating Doctor to be satisfied that the person meets all the eligibility criteria (See Section 2: *Eligibility criteria*)
  - a. Health eligibility criteria
  - b. Age criteria
  - c. Residency criteria
  - d. Nature of wish criteria
  - e. Decision-making capacity criteria
- 475. The first assessment is necessarily a thorough process. In some limited cases it may require only one assessment meeting, but it is likely to require more than one meeting with the person. As part of the first assessment process, the Coordinating Doctor:
  - a. must assess the person in order to determine their Communication Support needs and must make arrangements for the provision of that support (See Section on Communications Support).
  - b. may arrange meetings with the MDT to discuss the case and provide professional check and challenge (for further information see *Assisted Dying Multidisciplinary Team*), and / or
  - c. may arrange supporting assessments / opinions from a relevant professional outside of the Jersey Assisted Dying Service information (see *Supporting assessments / opinions from other professionals*), and / or
  - d. may arrange discussion with other relevant third parties such as family members or friends (see *Terms used connected person opinions*).

- 476. The law will set out that if the Coordinating Doctor is not satisfied that the person meets any of the eligibility criteria on the basis of their assessment and review of medical records alone, the Coordinating Doctor must seek further opinion or assessment from another relevant professional, with the person's consent.
- 477. A relevant professional is any professional that the assessing doctor is of the opinion has the necessary experience or expertise to provide an opinion on any matter that the assessing doctor determines is relevant to support them to make a decision as to whether the person meets the eligibility criteria. The professional may be based in Jersey or elsewhere. The professional may or may not have previously treated or provided care for the person being assessed. The professional may be a health and care professional, or any other professional that the assessing doctor considers relevant to provide advice or opinion to support them to make an eligibility determination. [See *Supporting assessments / opinions from other professionals*].

*For example*, if the person has terminal cancer, the Coordinating Doctor may need speak with the treating oncologist, or an independent oncology expert, to confirm that the person has a life expectancy of 6 months or less.

- 478. The law will provide that the Coordinating Doctor may request the relevant professional to:
  - a. undertake an assessment of the person, including potentially conducting any relevant tests or examinations
  - b. review the person's medical notes and / or treatment and care plan
  - c. provide general professional advice and opinion
  - d. undertake any other clinically appropriate investigation.
- 479. The law will set out that the Coordinating Doctor must inform the relevant professional that they are requesting the information in order to make a determination of eligibility for assisted dying. And the relevant professional may exercise their right to refuse and not provide a supporting assessment / opinion.
- 480. The Committee will develop the First Assessment Report form will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines they should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 481. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.)

482. The law will set out that during the first assessment, the Coordinating Doctor may make an initial determination of life expectancy to determine whether the person has 14 days or less life expectancy and if this is the case, the Coordinating Doctor may disapply the minimum timeframe during administrative review (Step 5) subject to requirements set out in *exception to minimum timeframe*.

#### First assessment decision

- 483. Where the Coordinating Doctor is satisfied that the person meets all the criteria above, they shall determine that the person is eligible for assisted dying, which will allow for the person to proceed to the next step (Independent Assessment).
- 484. The law will set out that once the Coordinating Doctor has completed the First Assessment, they must decide:
  - a. If they are satisfied that the person meets all the eligibility criteria and can proceed to the next step in process

OR

b. the person does not meet one or more of the eligibility criteria and cannot proceed to the next step in process.

#### Meets criteria

- 485. If the person is found to meet the criteria by the Coordinating Doctor, the Coordinating Doctor must inform the person / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that:
  - a. they have been found to meet the criteria and that
  - b. the person may progress to the next step in the process Step 3: Independent Assessment

# Does not meet the criteria

- 486. If the person is assessed as not meeting the criteria by the Coordinating Doctor, the Coordinating Doctor must inform the person as soon as practicably possible in writing and in a face to face meeting that:
  - a. their request for an assisted death has been refused and the reason/s it has been refused
  - b. the person may choose to appeal to the Royal Court [See instructions to follow Appeals]

- c. the person may request a Second opinion assessment but only if non-eligibility relates to the health criteria, not the age or residency criteria.
- 487. The Assessment Guidance will set out that Coordinating Doctor should advise the person as to what they, the Coordinating Doctor, thinks will be the likely outcome of the Second opinion assessment. For example, if the person has been found ineligible as they have a life expectancy of 5+ years, it is unlikely they will be found eligible by a Second Opinion Doctor, whereas, if they have been found ineligible based on the nature of their wish they may be likely to be found eligible in a Second opinion assessment. This is to help manage the expectations of the person.
- 488. If the person does not meet the criteria the Coordinating Doctor must complete the Refusal of Request form (see *Refusal of request*). The process will stop at the point at which the Coordinating Doctor completes the form.
- 489. The process cannot restart after the first assessment, having been stopped, unless after appeal or unless a Second Opinion Request Doctor finds that the person does meet the eligibility criteria.

#### Second opinion request

- 490. The law will set out that a person may request a second opinion assessment following a First Assessment where the Coordinating Doctor has determined that the person does not meet one or more of the eligibility criteria. This only includes the health, nature of wish or decision-making capacity criteria. It does not include where the Coordinating Doctor has determined that the person does not meet the age or residency criteria, as the Coordinating Doctor's determination is presumed to stand.
- 491. Where a person requests a second opinion, the Coordinating Doctor must make arrangements for that request to be reviewed by an assessing doctor who has not been involved in the person's request to date.
- 492. A second opinion request may only be made by the person. A third party (e.g.: family member or an attending practitioner or carer) cannot make a request for a second opinion on the grounds that they disagree with the determination that the person does or does not meet the criteria.
- 493. On receipt of a second opinion request, the assessing doctor will determine whether to:
  - a. accept the second opinion assessment request; or
  - b. refuse the second opinion assessment request.
- 494. The Assessment Guidance will provide information as to the matters to be considered by the assessing doctor when determining the circumstances in which a request may

be accepted or refused. This will include considering the clear and settled nature of the person's wish for an assisted death – it may be reasonable for the assessing doctor to determine that the request is not clear and settled, if a notable period of time has passed between the person being informed they did not meet the eligibility criteria and them making a request to a second opinion assessment.

- 495. A right to a second opinion will not be provided in law because of the potential that it could result in a vexatious use of resource, if a person who is clearly not eligible requests multiple second opinions.
- 496. The assessing doctor will not accept a request where they determine that it is reasonable to conclude that the outcome of the second opinion assessment will not differ from the first (i.e., that the person does not meet the criteria). It would, for example, be reasonable to reach such a conclusion if the person's treating physician was clear that life expectancy was 5 years.
- 497. In making the decision to accept or refuse the request the assessing doctor must review the person's First Assessment Report form, and may do any of the following, as they deem necessary for determining the request:
  - a. discuss with the Coordinating Doctor their reasons for not finding the person eligible
  - b. discuss with the person the reasons why the person believes they may be eligible, despite the findings of the Coordinating Doctor
  - c. discuss with any other relevant professional or connected person who was involved in the assessment process by providing a supporting assessment / opinion, or other relevant professional, as the assessing doctor deems necessary.
- 498. A person may request a second opinion either the end of the first assessment stage or independent assessment stage, OR at both the end of the first assessment stage and independent assessment stage. The process for determining the request and undertaking the Second Opinion Assessment is the same for both stages. The Assessment Guidance will set out matters to be considered where a second opinion is requested by the same person at the end of both stages of assessment, as this may indicate difficulties associated with a clear determination of eligibility which may, in itself, indicate a lack of eligibility.

# Second opinion request refused

- 499. If Assessing Doctor does not accept the person's second opinion request the Coordinating Doctor must inform the person / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that:
  - a. their request for a second opinion has been refused and the reason/s it has been refused

- b. that the process, which was stopped at the end of the first Assessment (on the completion of the Request Refusal form) remains stopped
- c. the person may choose to appeal to the Royal Court [See *Appeals*]
- 500. The Assessing Doctor may or may not be involved in informing the person that their request has not been accepted.

#### Second opinion assessment (if second opinion request accepted)

- 501. If Assessing Doctor accepts the person's request for a Second Opinion assessment the law will set out that a Second Opinion Assessment must be undertaken by a Second Opinion Doctor. The Second Opinion Doctor may be the assessing doctor who reviewed the second opinion request, or any other assessing doctor providing they have not been involved in the person's request to date.
- 502. Second Opinion Doctor:
  - a. will be provided the Coordinating Doctor's completed first assessment report form and all copies of supporting assessments / opinions that may have been undertaken during the first assessment process, and
  - b. must review this documentation
- 503. During the second opinion assessment, the Second Opinion Doctor is assessing the criteria which the Coordinating Doctor determined that the person did not meet (i.e., if Coordinating Doctor found that the person met the health criteria but not the capacity criteria, the Second Opinion Doctor is only assessing the capacity criteria).
- 504. The Second Opinion Doctor:
  - a. may determine that a person does not meet the eligibility criteria they are assessing on the basis of:
    - a review of the documents alone, OR
    - a review of the documents coupled with discussion with the Coordinating Doctor and / or the person and /or any professional who provided a supporting assessment / opinions and / or any connected person, OR
    - undertaking a full assessment (full assessment means repeating the whole assessment process)
  - b. may not determine that a person meets the criteria they are assessing unless they have undertaken a full assessment. The requirement for a full assessment is to safeguard against the risk of ineligible people being found eligible.
  - c. Where a Second Opinion Doctor determines a full assessment is required, they are assessing the health, nature of wish or decision-making capacity criteria.

- 505. It is for the Second Opinion Doctor to determine if a full first assessment is required. The person will not have a right in law to a full first assessment if the Second Opinion Doctor determines that one is not required.
- 506. The Second Opinion Doctor will complete a Second Opinion Assessment Report form.
- 507. The Second Opinion Assessment form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult

#### Second opinion determination: meets criteria

- 508. If the person is deemed as meeting all the eligibility criteria by the Second Opinion Doctor:
  - a. The Coordinating Doctor must inform the person / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that they have been found to meet the criteria and that
  - b. the person may progress to the next step in the process which may assessment by the Independent Assessment Doctor (Step 3) if the Second Opinion assessment was at the end of Step 2 or Second Formal Request (Step 4) if the Second Opinion assessment was at the end of Step 3.
- 509. The Assessment Guidance will set out that the Coordinating Doctor will need to decide if they should continue to act as Coordinating Doctor or transfer the role to another assessing doctor (whether or not this is the Second Opinion Doctor). The Coordinating Doctor will make this decision in discussion with the person (who may no longer have confidence in the Coordinating Doctor) and the second opinion doctor. If it is decided that the role should transfer, a Practitioner Transfer form must be completed (see below).

#### Second opinion determination: does not meet criteria

- 510. If Second Opinion Doctor determines the person does not the eligibility criteria, the Coordinating Doctor must inform the person / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting:
  - a. that the Second Opinion Doctor has determined that the person does not meet the eligibility criteria, and the reason/s why

- b. that their request is refused, which was previously refused will not be restarted
- c. that the person may choose to appeal to the Royal Court (See instructions to follow Appeals)
- 511. The Second Opinion Doctor may, or may not be involved in informing the person that their request has not been accepted.
- 512. A process which was not restarted after a Second Opinion assessment remains stopped unless after appeal it is found that the person does meet the eligibility criteria.

# Assisted Dying Multidisciplinary Team (MDT)

- 513. The law needs to provide for Assisted Dying Multidisciplinary Team members to register as assisted dying practitioners, as set out the associated registration requirements (see *-registration requirements*)
- 514. The law should not place a duty on an assessing doctor to establish an MDT to support any assessment process (i.e., the assessing doctor may or may not establish an MDT) but, where a Multidisciplinary Team is established by an assessing doctor it should provide that:
  - a. the function of that MDT is to support the assessing doctor in making a determination of eligibility by providing professional information and expertise from the perspective of the different professional disciplines.
  - b. that details of MDT meetings (date of meeting, name of attendees, summary of discussion including concluding findings and actions) should be documented in assessment report forms.
- 515. The law should not prevent a member of the MDT from both acting as a member of the MDT and, providing a supporting assessment or support opinion – as a professional in their own right - if asked to do so by an assessing doctor
- 516. Instead, the Assessment Guidance will state that for each assisted dying request, it will generally be the case that a Multidisciplinary Team (MDT), consisting of registered Assisted Dying Multidisciplinary Team members, will be formed to support the assessment process. (There may be some circumstances in which an MDT is not formed, for example, where the person is only expected to live for a few days, and it is evident that they meet the criteria)
- 517. Assessment Guidance will set out that the MDT will be chaired by the relevant assessing doctor and generally include a registered nurse, social worker and relevant allied health professionals (e.g., speech & language therapist or dietician), depending on the needs of the person.

- 518. Each member of the MDT will have undergone the assisted dying training and will be registered with the Assisted Dying Service.
- 519. If an MDT meeting is convened during the First Assessment stage it will chaired by the Coordinating Doctor (the Independent Assessment Doctor will not attend). If it is convened during the Independent Assessment stage it will chaired by the Independent Assessment Doctor (the Coordinating Doctor will not attend). Depending on the specifics of the person's request, the relevant assessing doctor who is chairing the meeting may also make a determination that other / different professionals need to be included in the MDT.
- 520. The Guidance will provide that the MDT established for the first assessment may be retained for the second assessment, or the membership may change in part, or completely, as the Independent Assessment Doctor, or Second Opinion Doctor determines is appropriate, as chair and convener of the MDT.
- 521. The assessing doctor who is chairing the MDT will determine the frequency that the MDT meets during the assessment process, depending on the complexity of the case. The Assessment Guidance produced by the Committee will set out in detail how the MDT will operate.
- 522. All MDT meetings will be formally documented to provide a record of the discussions which will be included in the assessment report forms.
- 523. The purpose of the MDT is to provide check and challenge for the assessing doctors and a multidisciplinary perspective to discussions of eligibility. The MDT meetings can be used to discuss if additional supporting assessments / opinions may be required, and identify professionals who are best placed to provide theses supporting assessments / opinions.
- 524. The MDT will also be a forum to discuss additional support that the person may require, this could be either:
  - alongside the person's engagement in the assisted dying process for example, if the person would benefit from access to counselling services; or
  - b. where the person is likely to be assessed as ineligible for assisted dying, the MDT may consider signposting to other services – for example, if there are safeguarding concerns around financial abuse, a safeguarding referral should be instigated, and where there are ongoing social care needs, a referral for social care assessment should be instigated.
- 525. The assessing doctor may request that an MDT member provides a formal supporting assessment / opinion of the person. However, the determination of eligibility in the First and Independent Assessment will be made by the Coordinating Doctor and Independent Assessment Doctor respectively. (Conversely, the assessing doctor may also seek a supporting assessment / opinion from a professional who is not a

member of the MDT. For example, an MDT social worker may input into MDT meetings, and support a person with onward referral if they are assessed as ineligible, but a non-MDT social worker may undertake an assessment of coercion / family dynamics.)

# Professional supporting assessments / opinions

- 526. The law will provide that an assessing doctor (Coordinating Doctor, any Second Opinion Assessment Doctor, Independent Assessment Doctor) must seek a professional supporting assessment / opinion of specific matters related to a person's eligibility for assisted dying, where the assessing doctor is <u>unable to make a determination</u> of that specific matter.
- 527. This must be a professional whose opinion the assessing doctor deems to be relevant to support the assessing doctor to determine the matter this could be:
  - a. a member of the assisted dying MDT,
  - b. a professional outside of the Jersey Assisted Dying Service (whether or not they are another attending practitioner or carer)
  - c. an assisted dying practitioner providing they are not an involved professional (i.e., are not involved in the assisted dying process for a specific individual)
  - d. a Jersey based / non-Jersey based professional
- 528. If the assessing doctor is able to make a determination of all necessary matters there will be no requirement in law to seek a professional supporting assessment / opinion.
- 529. The professional carrying out the supporting assessments or providing the supporting opinions will not be determining whether the person is eligible / not eligible for assisted dying.
- 530. They will be providing their opinion on specific matters which they are deemed qualified to assess / provide opinion on, in order for the assessing doctor to consider that opinion as part of the assessing doctor's determination of eligibility for an assisted death.
- 531. The law should be clear that the assessing doctor:
  - a. must have regard to the assessment / opinion but, their determination of eligibility does not necessarily have to accord with the assessment / opinion (they may, for example, weigh the assessment / opinion against other evidence and determine that the assessment / opinion is not a decisive factor)
  - b. may request supporting assessments / opinions, on the same specific matter, from more than one professional
  - c. must document on the Assessment Form details of any supporting assessments / opinions requested and provided, including:

- name and role of professional
- description of assessments / opinions requested
- reason for request
- reasons for making a determination that does not accord with the assessment / opinion
- 532. Professionals who are not based in Jersey may provide a professional supporting assessment / opinion for example a UK-based medical consultant may provide information about the person's prognosis / life expectancy, but it is anticipated the consultant would need to undertake such an assessment in Jersey, and as such be registered in Jersey as a medical practitioner.
- 533. The law will set out that the assessment / opinion provided may relate to:
  - a. the person's medical history, diagnosis, treatment options (for example, a respiratory consultant may provide opinion on treatment and care options), or
  - b. the person's decision-making capacity to make the request for an assisted death, or
  - c. the voluntary, settled and informed nature of the person's wish (for example, a social worker providing an opinion on the context of family circumstances and the voluntariness of the person's request)
  - d. any other matter the assessing doctor deems relevant, in order to support the assessing doctor to make a determination of the person's eligibility for assisted dying.
- 534. Those providing professional support assessments / opinions are not required to be registered assisted dying practitioners (and hence, are not required to have undertaken the assisted dying training)
- 535. The law will set out the professional providing the supporting assessment / opinion must be informed by the requesting assessing doctor that the assessment / opinion relates to an assisted dying request. As set out in *Right to refuse to participate in the assisted dying process* section, the professional has a right to refuse provide the assessment / opinion.
- 536. Where the professional agrees to provide their opinion, they must complete a Specific Person Declaration of Interest Form (see section on *Specific Person Declaration of Interest Form*)
- 537. If any interests are declared, it will be for the Reviewing Officer to determine if it represents a degree of conflict which means the professional should not provide the supporting assessment / opinion, or in the event that it has already been provided, whether the Reviewing Officer should direct the assessing doctor to seek the opinion of an alternative professional.

538. The necessary information sharing consents must be in place, for them to do so. Where the person chooses not to provide the necessary information sharing consent there can be no supporting assessment / opinions, and the person must be informed that this may mean the assessing doctor is unable to determine eligibility.

#### Transferring the role of assessing doctor or Administering Practitioner

- 539. The law will set out that the role of assessing doctor or administering practitioner may be transferred to another assessing doctor or administering practitioner at any point in the request, assessment and approval process.
- 540. For clarity, Assessment Guidance will set out that any transfer of practitioner should be discussed with the person and their wishes taken into account, or the person may raise the issue and request a transfer for any reason, but the law will not provide a right for the person to request a transfer of practitioner.
- 541. Transfer of the role may be required if, for example:
  - a. the assessing doctor or administering practitioner declares a conflict of interest that the Reviewing Officer determines, or the professional themselves determines, would impact on their ability to act in the role
  - b. a Coordinating Doctor determines that the role should transfer following a second opinion assessment which determines a person is eligible for assisted dying
  - c. an unforeseen circumstance occurs (e.g., long term sickness, unplanned absence)
  - d. the professional wishes to recuse themselves for any other reason.
- 542. If a role needs to be transferred, a Practitioner Transfer Form must be completed before the incoming practitioner can take up the role, this must be signed by the outgoing and incoming practitioners, where possible and as soon as practicably possible.
- 543. The 'outgoing' practitioner must inform / make arrangements to inform the person of this transfer as soon as practicably possible.
- 544. The Practitioner Transfer form will be developed by the Committee and include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister

- c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 545. The form will be in such a format as the Committee decides (i.e., electronic, paper etc.)

# Step 3: Independent assessment

- 546. If, at the end of Step 2, the person is deemed to meet the criteria (whether by the first Coordinating Doctor or the Second Opinion Doctor), the person may proceed to Step 3; Independent assessment
- 547. Before an independent assessment can commence the person must have confirmed they wish to proceed to the independent assessment by signing (instructing their signatory to sign) the Step Transition form (see *Step Transition Forms*).
- 548. The independent assessment must be undertaken by an Independent Assessment Doctor. The Independent Assessment Doctor is an assessing doctor who has not, in relation to the person's request, undertaken the role of Coordinating Doctor or Second Opinion Doctor.
- 549. The Independent Assessment Doctor may, however, have provided a supporting assessment / opinion as part of the First Assessment. Any opinions or supporting assessments provided during the First Assessment would not be a determination of the person's eligibility at that stage, but rather input into a specific matter, as requested by the Coordinating/Second Opinion Doctor due to their expertise/experience. Any activity carried out as part of that supporting assessment / opinion would not contradict any of the duties/requirements of the professional in carrying out their role as the Independent Assessment Doctor.
- 550. The law will set out that:
  - a. the Independent Assessment Doctor must, independently of the Coordinating Doctor, (and the Second Opinion Doctor, if relevant) form their own opinions on whether the person meets the eligibility criteria. This does not include the age or residency criteria as the Coordinating Doctor's determination of these to matters is presumed to stand
  - b. the purpose, format and matters to be assessed during the Independent Assessment are same as the first assessment
- 551. For the purpose of clarity, the Independent Assessment Doctor is not determining whether they agree / disagree with the Coordinating Doctor's assessment (or providing

opinion as to how the Coordinating Doctor undertook the first assessment) they are making their own determination of eligibility.

- 552. In undertaking the Independent Assessment, the Independent Assessment Doctor may:
  - a. request any supporting assessments / opinions they deem necessary to supporting their determination (this may be from professionals who have already been consulted during the first assessment or from other professionals not previously consulted), and / or
  - b. access any documentation arising from supporting assessment / opinion requests made by the Coordinating Doctor (and / or the Second Opinion Doctor) during the First Assessment , and /or consult persons involved in the first assessment (including, for example, the Coordinating Doctor and / or the Second Opinion Doctor and / or members of the MDT and / or any other person engaged in the first assessment process) about matters relating to the person or the person's eligibility to meet the criteria
- 553. Whilst the Independent Assessment Doctor may consult with the Coordinating Doctor on any matter regarding the First Assessment, they may not have access to the First Assessment Form completed by the Coordinating Doctor. Access to the First Assessment Form, and all the associated detail, has greater potential to subconsciously influence the Independent Doctor's assessment than simply consulting with the Coordinating Doctor.

# Note to law drafting officer:

P18/2024 stated that the Independent Assessment Doctor would not have access to the First Assessment Form completed by the Coordinating Doctor.

In developing these instructions, this matter is to be given more detailed consideration with the Professional Leads group supporting the development of this work. What needs to be established is whether denying access to the First Assessment Form is a valuable measure as it safeguards against 'group think' or a false safeguard because the Independent Assessment Doctor will inevitably liaise with the Coordinating Doctor who is likely to impart the information recorded on the First Assessment Form

- 554. As set out above (*Communications Support*), the law will set out that the Independent Assessment Doctor will have a duty to consider matters related to the person's requirement for communications support.
- 555. The Independent Assessment Doctor must complete an Independent Assessment Report form which will form part of the person's assisted dying person records.
- 556. The form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 557. The law will set out that during the independent assessment, the Independent Assessment Doctor may make a determination of life expectancy to determine whether the person has 14 days or less life expectancy and if this is the case, the Coordinating Doctor may disapply the minimum timeframe during administrative review (Step 5) – subject to requirements set out in *exception to minimum timeframe*.

#### Post independent assessment

- 558. Once the Independent Assessment Doctor has completed their assessment, they must:
  - a. determine whether the person meets all the eligibility criteria
  - b. inform the Coordinating Doctor of their decision and the grounds for that decision

#### Does not meet the criteria

- 559. If the person is assessed as not meeting the criteria by the Independent Assessment Doctor, the law should provide that the Coordinating Doctor:
  - a. must inform / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that:
    - the Independent Assessment Doctor determined they were not eligible, and the reasons for that determination
    - the person may choose to appeal to the Royal Court [See instructions to follow *Appeals*]
    - the person may request a Second opinion assessment but only if noneligibility relates to the health criteria, not the age or residency criteria.

- 560. Whilst the law will not stipulate that the Independent Doctor must be involved in informing the person about their determination, the Assessment Guidance will set out that, it is recommended they are involved unless there are compelling grounds not to involve them (for example; distress to the person). The Assessment Guidance will also set out that the Coordinating Doctor should advise the person as to what they, the Coordinating Doctor, thinks will be the likely outcome of the Second opinion assessment. This is to help manage the expectations of the person.
- *561.* If the person does not meet the criteria the Coordinating Doctor must complete the refusal of request form [see *Refusal of Request*] and the process will stop.
- 562. The process cannot restart after the independent assessment, having been stopped, unless after appeal or unless a Second Opinion Request Doctor finds that the person does meet the eligibility criteria.
- 563. If the person chooses to request a Second Opinion Assessment, this will follow the process outlined in from paragraph 490.

#### Meets criteria

- 564. If the person is found to meet the criteria by the Independent Assessment Doctor (or the Second Opinion Doctor where relevant) the Coordinating Doctor must inform the person / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that:
  - a. they have been found to meet the criteria and that
  - b. the person may progress to the next step in the process Step 4: Second Formal

# Step 4: Second formal request

- 565. Before the Second Formal Request can be made the person must have confirmed they wish to proceed to this Step by signing (instructing their signatory to sign) the Step Transition form.
- 566. The second formal request acts as confirmation of the person's enduring wish for an assisted death and will take the form of a written declaration.
- 567. The Second Formal Request is a process which involves the person:
  - a. discussing with the Coordinating Doctor their prognosis, treatment options and their wish for an assisted death. It culminates in the person deciding if they want to make a second formal request. This may involve one meeting between the person and the Coordinating Doctor (which may or may not be part of the meeting in which the person is informed that the Independent Assessing Doctor has found

them eligible for an assisted death) or multiple meetings over a protracted period of time.

b. making a decision to make a second formal request an assisted death

#### Does not make a second formal request

- 568. If the person does not inform the Coordinating Doctor if they want to make a second formal request, the Jersey Assisted Dying Service will not take any action.
- 569. If the person informs the Coordinating Doctor they have decided not to make a second formal request, the Coordinating Doctor will confirm with the person that they wish to make a withdrawal of request (see *Withdrawal of Request*), and the process will stop. If the person changes their mind at a later date, they will have to start the assisted dying process again (i.e., return to Step 1) i.e., the process cannot restart.
- 570. The Coordinating Doctor will sign and complete a Withdrawal of Request Form.

#### Makes a second formal request

- 571. The second request must be voluntary, clear, settled and informed and the person must have decision-making capacity to make the request (assisted dying decision see *section 2 eligibility criteria*). The person must make the second formal request by signing (instructing their signatory to sign) the Second Formal Request form in the presence of:
  - a. a witness; and
  - b. the Coordinating Doctor
- 572. For the purposes of clarity, the Second Formal Request form must be signed and dated by the person (their signatory), the Coordinating Doctor, and the witness in the presence of each other.
- 573. The Second Formal Request Form will record the person's consent for the Coordinating Doctor to proceed to Step 5 (Administrative review).
- 574. The Second Formal Request form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult

- 575. The Coordinating Doctor may refuse a person's second formal request (i.e., the Coordinating Doctor is not required to accept the request) if during the course of the second formal request meeting/s the Coordinating Doctor has reasonably believes the person's request is not voluntary, clear, settled or informed or the person does not have capacity to make an assisted dying decision.
- 576. If the Coordinating Doctor refuses the person's request, they must complete a Refusal of Request form, and the process will stop.
- 577. The process cannot restart having been stopped on refusal of the Second Formal request unless after appeal, it is found that the person's request is voluntary, clear, settled or informed or the person does have capacity to make an assisted dying decision, contrary to the determination of the Coordinating Doctor.
- 578. The witness plays no role with respect to the assessment of eligibility or application of other safeguards.
- 579. A witness is not required at the making of the first formal request as the primary purpose of the first formal request is to start the formal assessment process, whereas the second formal request has more significant implications as it is signifies the person's continued intent to have an assisted death prior to approval.
- 580. The law will set out that the witness must be someone who knows the person sufficiently well, so that they (the witness) feels able to attest to the fact that the person is acting voluntarily and their wish is clear, settled and informed. This may be, for example:
  - a. an attending practitioner or carer who is providing care and treatment to the person but has not been involved in the person's assisted dying process
  - b. someone who knows the person in a personal capacity or professional (e.g.: a friend, neighbour, work colleague)
- 581. The witness may not be:
  - a. a known beneficiary of the person 's Will, or believe they may be a potential beneficiary
  - b. a person who may otherwise benefit financially or in any other material way from the death of the person; or
  - c. a family member of the person; or
  - d. an involved professional.
- 582. For clarity, a family member of the person is intended to include a partner or relative with a close degree of connection, including:
  - a. Husband/wife/spouse/partner

- b. Child/Parent (including, adoptive child and former adoptive child)
- c. Grandchild/grandparent (including adoptive grandchild and former adoptive grandchild)
- d. Sibling
- e. First cousin
- f. Parent's sibling i.e. aunt/uncle
- g. Sibling's child i.e. nephew/niece

# Step 5: Administrative Review by Coordinating Doctor (approve or refuse)

- 583. Before the Administrative Review Process can commence the person must have confirmed that they consent to the Coordinating Doctor proceed to Administrative Review by signing (instructing their signatory to sign) the Second Formal Request form.
- 584. The administrative review step consists of the Coordinating Doctor:
  - a. satisfying themselves, to the best of their ability, that the assisted dying process has been complied with. They will do this having checked that relevant forms have been properly completed and the two formal requests are in place, and
  - b. having satisfied that the process has been complied with, determining whether to approve or refuse the person's request for an assisted death.
- 585. Note: In this section of the instructions references to process should be taken to mean "process to date" as the Coordinating Doctor cannot make any determination as to matters that will occur in later steps. The law will set out that this must include review of the assisted dying person record, including all relevant forms and supporting information.
- 586. The law will state that the Coordinating must take action if they determine it is necessary to satisfy themselves that the process complied with. Reasons that they may not be satisfied include, for example:
  - a. any of the relevant documentation is found to be not in place or is incorrect,
  - b. the Coordinating Doctor identifies any errors of process
  - c. identifies that any relevant information has been / may have been overlooked
  - d. identifies that the person is not eligible (for example, if some critical information has been overlooked).
- 587. The list above is not exhaustive, there may be other reasons why the Coordinating Doctor is not satisfied.

- 588. The actions that the Coordinating Doctor may take include:
  - a. repeating / making arrangements to repeat a Step / part of a Step in the process if the Coordinator Doctor deems it necessary (for example; they may determine that the Independent Assessment needs to be repeated by a different assessing doctor if a declaration of interest was not properly determined)
  - b. making arrangements to secure a supporting assessment / opinion where they believe this should have previously been secured
  - c. consulting with the relevant person to determine why documentation is not complete / contains errors / has been overlooked and, having consulted the relevant person determining what action is required to resolve the problems identified
  - d. seeking advice from the office of the attorney general or another third party (for example, the Jersey Care Commission).
- 589. The list above is not exhaustive, there may be other actions that the Coordinating Doctor determines they should take in order to satisfy themselves that the process has been completed in accordance with the law.
- 590. In the event of any delays completing the Administrative Review Step, which is likely in the event that action is required, the Coordinating Doctor must ensure the person is kept fully informed.
- 591. The Coordinating Doctor must record on the Administrative Review (approve or refuse) Form:
  - a. if they have reviewed all the relevant documents
  - b. what action they have taken, if any, post that review
  - c. the reasons for any action and the outcomes of any action
  - d. whether having undertaken the review (including reviewing the outcomes of any actions taken) they:
    - are satisfied that the process has accorded with the law and all the necessary documentation is in place, OR
    - are not satisfied that process has accorded with the law or that all the necessary documentation is in place
- 592. If the Coordinating Doctor is still not satisfied that the process has been in accordance with the law despite action taken to satisfy themselves, they cannot make a final determination as to whether the person meets all the eligibility criteria in law. IN the event they cannot make a final determination, they cannot approve the person's request for an assisted death.

- 593. If the Coordinating Doctor is satisfied the process has been in accordance with the law, they must then proceed to make a final determination as to whether the person meets all the eligible criteria in law. If they determine:
  - The person meets all the eligibility criteria in law, they must approve the person's request for an assisted death (this is known as 'request approval')
  - The person does not meet all the eligibility criteria in law, they cannot approve the person's request for an assisted death.
- 594. For the purposes of clarity, no person may have an assisted death in Jersey unless they have request approval; request approval can only be provided by the Coordinating Doctor; the Coordinating Doctor can only provide request approval if the Coordinating Doctor has determined that the person meets all the eligibility criteria in law; the Coordinating Doctor cannot determine that the person meets all the eligibility criteria unless the Coordinating Doctor is satisfied that the assisted dying process has been undertaken in accordance with the law.
- 595. If Coordinating Doctor does not approve the request, the law will set out that the Coordinating Doctor must:
  - a. sign the request refused section on the Administrative Review (approve or refuse) Form. There is no requirement to also complete a Request Refusal form
  - b. must inform / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that:
    - their request for an assisted death has been refused and the reason/s it has been refused
    - the process has now stopped
    - the person may choose to appeal to the Royal Court [See instructions to follow *Appeals*]

Note: at this stage in the process, there is not Second opinion option

- 596. The process cannot restart after the administrative review, having been stopped, unless after appeal.
- 597. If Coordinating Doctor approves the request, the law will set out that the Coordinating Doctor must:
  - a. sign the request approval section on the Administrative Review (approve or refuse) Form
  - b. must inform / make arrangements to inform the person as soon as practicably possible in writing and in a face-to-face meeting that their request for an assisted death has been approved.

- 598. The Coordinating Doctor must complete an Administrative Review (approve or refuse) Form, which will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 599. Before Assisted Death Care Planning can commence the person, who has approval of request, must have confirmed they wish to proceed to this Step by signing (instructing their signatory to sign) the final Step Transition form.
- 600. In signing the final Step Transition form, the person is making a decision to have an assisted death (having had the necessary approvals). The person is required to make a declaration of their decision to have an assisted death on the form. For example, *I* declare that it is my decision to have an assisted death. I voluntarily make this decision and fully understand that proceeding to have an assisted death will result in my death. I wish to commenced planning for that assisted death

#### Expiry of approval

- 601. Once a person has approval of request the law will set out that there will be no expiry date for this approval.
- 602. Approaches to expiry of approval varies by jurisdiction, but there is no expiry date associated with approvals in most other jurisdictions; New Zealand being an exception where approval expires six months after the date initially chosen for the administration of the substance.<sup>52</sup>
- 603. The decision to not include an expiry date is a safeguard, so that pressure is not placed on the person to end their life through an assisted death when they are not yet ready to do so, purely because their approval is close to expiry.
- 604. An approval for an assisted death can have a palliative effect, providing the person with a sense of control over the end of their life. Evidence from other jurisdictions suggests that, in some cases, the knowledge that a person has the option to end their suffering brings such comfort that they choose not to proceed to an assisted death. For example, in Western Australia in 2022 around 28% of people who were approved for an assisted death, did not go on to have an assisted death.<sup>53</sup>

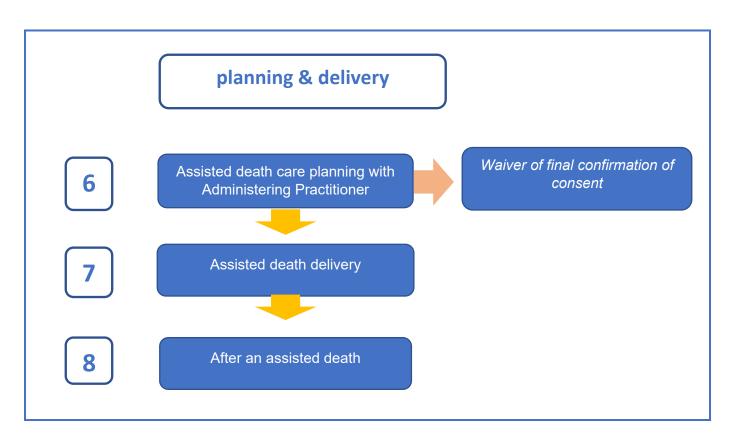
<sup>&</sup>lt;sup>52</sup> End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 20 Administration of medication – <u>New Zealand Legislation</u>

<sup>&</sup>lt;sup>53</sup> Voluntary Assisted Dying Board Western Australia Annual Report 2022-23 (health.wa.gov.au)

# 7. Assisted dying process – planning and delivery of an assisted death

This section details Steps 6 to 8 - how a person, who has approval of request, will be supported to plan for their assisted death; the process for prescribing and dispensing the assisted dying substance; provision of the assisted death; post-assisted death processes and arrangements.

In this section, elements highlighted in grey, set out policy to be incorporated in the professional guidance, as opposed to covered explicitly by law. The information is included in these instructions for completeness and to help fully articulate the assisted dying process.



Process steps for planning and delivery of an assisted death

# Step 6: Assisted Death Care Planning

#### Assisted Death Care Planning

- 605. During the planning step (Step 6) and delivery step (Step 7) the Administering Practitioner (as distinct from the Coordinating Doctor) becomes the principal clinician responsible for the assisted dying process.
- 606. The law will set out that the Administering Practitioner
  - a. must be registered as such on the assisted dying register
  - b. may have also acted as Coordinating Doctor for the person
  - c. may have supported assessment process as a member of the MDT team in relation to the person
  - d. may have provided a professional supporting assessment / opinion
  - e. may not have acted as Independent Assessment Doctor for the person as, by definition, the independent assessment doctor is required to have a degree of independence
- 607. The law will set out that the Administering Practitioner:
  - a. will, in consultation with the person, prepare an assisted death care plan which will set out person's wishes and preferences for their assisted death (as far as practically possible)
  - b. must ensure that the assisted death care plan accords with the law.
- 608. The Assisted Death Care Plan will be recorded on the Assisted Death Care Plan form. The Assisted Death Care Plan form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 609. The Assisted Death Care Planning Guidance will be developed by the Committee.
- 610. The Assisted Death Care Planning Guidance will confirm that any discussions with the person about their wishes for their assisted death that began during previous steps may continue throughout the process and will have been recorded on the assessment forms. The Administering Practitioner will review any such information record on the forms prior to meeting with the person to develop their Assisted Death Care Plan. In

many cases, the assisted death care planning process will consist of confirming the person's previously stated wishes that were recorded on the assessment forms.

- 611. The law should not prevent informal consideration of planning for an assisted death during the request and assessment steps. Assessment Guidance and Care Planning Guidance will set out that the assessing doctors would capture such details on the assessment forms.
- 612. The law will set out that the Assisted Death Care Plan form must include confirmation by the Administering Practitioner that they have informed the person of:
  - a. the person's options for the method (self-administered or practitioner administered) and mode (oral or intravenous administration) of an assisted death, including discussion of the assisted dying substance that will be used and how it will be administered
  - b. options for method/mode available to the person and why any particular option may or may not be suitable for the person, so that the person can give informed consent for the agreed method and mode of assisted death
  - c. potential harms, risks or medical complications resulting from administration of the assisted dying substance
  - d. administration/self-administration of the assisted dying substance is intended to result in the person's death
  - e. the person's options to provide consents or waivers, including:
    - Confirmation of Consent to Proceed
    - Waiver of Final Confirmation of Consent
    - Any Advance Decision to Refuse Treatment (ADRT), including a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation)
    - whether they may be suitable as an organ donor (Note: there will not be an explicit requirement for the Administering Practitioner to discuss organ donation in all cases, as in many case the person's organs will not be suitable for donation.)
- 613. And further to this, the law should provide that the Assisted Death Care Plan form must record
  - a. whether the person has provided:

- Confirmation of Consent to Proceed
- Waiver of Final Confirmation of Consent
- Any Advance Decision to Refuse Treatment (ADRT), including a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation)

b. that arrangements have been made for an ADRMP to visit the person, within the statutory timeframe and prior to the planned date for the assisted death (see section *Step 8 – After an assisted death*)

- 614. It is envisaged that the Minister will prescribe by Order, the following details of the Assisted Death Care Plan to be recorded on the Assisted Death Care Plan form. To include:
  - a. the person's preferred method for an assisted death and mode of delivery
  - b. the name / s assisted dying practitioners who will be present at the assisted death. This must include the:
    - Administering Practitioner
    - administration witness
  - c. the names of any other persons who will be present at the death (such as family members or friends) including
    - their relationship to the person
    - how they will be supported to understand what happens during the dying process
    - what, if anything, the person wishes them to do in the lead up to the administration of the substance, during the administration, post administration and post death (or example, supporting the person to self-administer the substance by holding cup, playing particular music)
  - d. any cultural / religious considerations and rituals that are important to the person and their family and that they wish to observe at the bedside
  - e. the location where the person wants to be at the end of their life, and alternative locations, in the event that the death cannot take place in the preferred location
  - f. the planned time and date for the administration of the substance (note; this many not be the date of death as the dying process may take a number of hours post administration of the substance)
  - g. any matters related to organ donation arrangements and wishes

- 615. The law will provide the Assisted Care Death Plan form must be signed by the person (their signatory) and the Administering Practitioner in the presence of each other. In signing the form, the Administer Practitioner must declare they are satisfied that the person has decision-making capacity.
- 616. The law will provide that, in signing the form the person is consenting to proceed to Step 7, the administration of the assisted dying substance / support to self-administer the assisted dying substance. Note: at Step 7 they will be required to provide final consent)
- 617. The law will provide that the following changes may be made to a signed Assisted Care Death Plan form, any point, up to the administration of the substance, in the following circumstances:
  - a. the person may change their mind about any of the matters agreed on the care plan
  - b. should the person's circumstances change for example a deterioration in the person's condition, the Administering Practitioner may recommend a change in the Care Plan, for example a change from self-administration of the substance to practitioner administration.

Any updates must be signed by the Administering Practitioner and the person (or their signatory)

618. The law will set out that Administering Practitioner should seek to ensure that the assisted death adheres to the person's wishes, as set out in the Assisted Care Death Plan form, where practicably possible but they may deviate from the Plan where Administering Practitioner deems it necessary to do so for clinical, practical or other reasons for example the person is unexpectedly moved to hospital and therefore the person's wish to have an assisted death at home may not be possible.

# Approval of location

- 619. The law will provide that the Administering Practitioner must approve the location at which an assisted death is to take place. For the purposes of clarity, that approval will be for a specific assisted death, as opposed to assisted deaths in general (i.e., there will not be a standing approval for any assisted deaths to take place in a specific nursing home')
- 620. Locations for an assisted death could include:
  - a. private homes

- b. any facility owned by GoJ or managed by GoJ
- c. care and nursing facilities whether or owned or managed by GoJ. This may include privately owned, parish-owned or owned by a charity or community organisation, noting that premises operators are provided a right to refuse see paragraphs 239-246]
- d. hospital facilities.

621. A location cannot be approved by the Administering Practitioner unless:

- a. the premises operator has given permission for an assisted death to take place at that location, where that location is an adult care home service regulated by the Jersey Care Commission under the Regulation of Care (Jersey) Law 2014 that is not operated by Government of Jersey
- b. the Administering Practitioner is satisfied that an assisted death can be safely carried out in that location, taking into consideration:
  - i. the suitably of that location for administering the assisted dying substance. For example:
    - if there are risks present in the location (e.g., from the presence of potentially aggressive dogs; other occupants who may have learning difficulties and who are unable to understand what is happening)
  - ii. the views of any other person that resides in the property. For example:
    - *if there are people who live in the property who are opposed to assisted dying, the Administering Practitioner will need to consider whether that may result in disruption and / or distress and / or potential harm to the person or the other occupants*
- 622. The Committee will make arrangements to develop, and will approve and publish Location Guidance which will set out the matters that must be considered in approving a location, the identification of any risks and associated mitigations.
- 623. For example, if the assisted death is to take place in a care facility, there will need to be consideration of other individuals that may be present or close by during the assisted death (for example, persons and staff in the same hospital ward, even if the assisted death takes place in a private room).
- 624. The Guidance will set out that if the person's choice of location cannot be approved or is unlikely to be approved by the Administering Practitioner, the Care Navigator will work to identify an alternative preferred location for the person to consider.

# Confirmation of consent to proceed

- 625. Confirmation of consent to proceed allows an Administering Practitioner who is present at the assisted death to take an appropriate intervention in the event the person loses decision-making capacity during the process of administering the substance but does not die.
- 626. For example, a person who has opted to self-administer the substance may digested some of the substance, but not all, before losing consciousness. In these circumstances, if the person has provided confirmation of consent to proceed, the Administering Practitioner may, for example, administer additional substance intravenously.
- 627. As part of the Assisted Death Care Planning step, the Administering Practitioner will discuss with the person the option to provide specific consent for the administering practitioner to:
  - a. prepare alternative modes of administration, i.e., insert an IV line even where the person has opted to take the assisted dying substance orally.
  - b. administer additional assisted dying substance intravenously, in the event of either:
    - medical complications that prevent the completion of the assisted death, including regurgitation and vomiting, or seizure
    - delayed effectiveness of oral medication, where the person has not died within 60 minutes of taking the substance orally.
- 628. This consent (known as confirmation of consent to proceed) will be recorded on the Assisted Death Care Plan Form
- 629. For clarity, whilst the person will not be required to provide confirmation of consent to proceed. Any consent given must be recorded by the Administering Practitioner on the Assisted Death Care Plan.
- 630. Prior to the Assisted Death Care Planning Step, the law will require the Coordinating Doctor to provide the person information about confirmation of consent to proceed as part of the *Approved Information* and assessment process.

# Waiver of Final Confirmation of Consent

631. The law will provide that a person who has request approval may make a Waiver of Final Confirmation of Consent. This allows a person to decide in advance that, if they lose decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE giving final consent (at Step 7), the assisted death can still take place.

- 632. The rationale for Waiver of Final Confirmation of Consent is that it ensures a person, who has request approval will not be prevented from having their request fulfilled (in accordance with agreed arrangements) in the event they no longer decision-making capacity in relation to an assisted dying decision.
- 633. The law will provide that the Waiver of Final Confirmation of Consent:
  - a. takes the form of a written declaration, which will form part of the Assisted Death Care Plan Form. The person may, or may not, choose to make a declaration
  - b. the declaration is not valid until the Assisted Death Care Plan form has been completed and signed by the person (their signatory) and the Administering Practitioner. This is because the Form sets out the planned date, location and mode for the person's assisted death – and without this information the Administering Practitioner cannot know how to fulfil the person's request for an assisted death.
- 634. The law will provide that:
  - a. where a person has made a declaration of Waiver of Final Confirmation of Consent, and that person losses capacity before they give final consent (as part of the Final Review process) the Administering Practitioner <u>may</u> proceed to administer the assisted dying substance
- 635. The law will further provide that:
  - a. if the Administering Practitioner is administering the substance to a person who has lost capacity (where a Wavier is in place) they should seek to do so in accordance with the Assisted Death Care Plan but they can do so in a manner which does not accord with the Assisted Death Care Plan where the Administering Practitioner deems it is necessary, for example, they may deem it necessary to change the way the substance is administered in recognition of the deterioration in the person's health.
  - b. even if the person has in place a Waiver of Final Confirmation of Consent in place the Administering Practitioner should not administer the substance if, during the Final Review or in the lead up to the assisted dying substance being administered, the person demonstrates a refusal or resistance to the administration by words, sounds or gestures (for clarity, reflexes and other types of involuntary movements, such as response to touch or the insertion of a needle, would not constitute refusal).

636. For the purpose of clarity:

- a. the law should not compel the Administering Practitioner to administer the assisted dying substance even where the person has made a declaration of Waiver of Final Confirmation of Consent, if the Assisted Dying Practitioner deems there are compelling reasons for not doing so (for example, the person is distressed; the person is unconscious, on the cusp of death, and clearly pain free).
- b. the person is not required to provide Waiver of Final Confirmation of Consent. If they do not, and they lose capacity after request approval and before / at the time of giving final consent (Step 7), the assisted death cannot take place.
- 637. The wording of the declaration of 'Waiver of Final Confirmation of Consent', which will form part of the Assisted Death Care Plan Form.
- 638. Assisted Death Care Planning Guidance will state that the Administering Practitioner should inform the person about the option to make a declaration of Waiver of Final Confirmation of Consent, and if the person is at risk of losing their ability to give consent to assisted dying the Administering Practitioner must inform them of this.

# Advance Decision to Refuse Treatment

- 639. Advanced decisions for an assisted death will not be permitted in law but Advance Decisions to Refuse Treatment (ADRT) will be recognised as in any other end of life circumstances in Jersey.<sup>54</sup>
- 640. As part of the care planning process, the Assisted Death Care Planning Guidance will state that the Administering Practitioner must discuss with the person whether the person wishes to have in place an Advance Decision to Refuse Treatment (ADRT). An ADRT could include a DNACPR do not attempt cardiopulmonary resuscitation providing clear instruction to health care providers that the person does want to be resuscitated if the person requires emergency medical treatment during any step of the assisted dying process.
- 641. The law will set out that the Administering Practitioner must arrange for a dedicated assisted dying registered medical practitioner (ADRMP *see Step 8 After an assisted death*) to attend to the person, if this has not already taken place, or if it took place more than 14 days before the planned date of the person's assisted death.

<sup>&</sup>lt;sup>54</sup> Advanced decision to refuse treatment (ADRT) (gov.je)

642. The ADRMP, who will be responsible for certifying the death of the person, must by law have attended the person within the 14 days prior to their death, in line with requirements under Article 64 of the Marriage and Civil Status (Jersey) Law 2001.

**To note:** Law drafting officers should note that draft Law Drafting Instructions on amendments to the statutory provisions for Death Management, propose extending the period of attendance prior to death to 28 days. Should this be agreed in the draft law amends related to the Death Management project, the assisted dying law should have the flexibility to mirror these changes – i.e. extended the timeframe to 28 days. At present it is anticipated that these changes would come into effect by 2026, i.e. before the implementation of assisted dying (c. Summer 2027).

643. The law will set out that the Administering Practitioner must ensure that the Jersey General Hospital Pharmacy is informed as soon as practicably possible of the intended time, date and location of the assisted death, and the agreed method/mode of administration of the substance. This should be confirmed after the Assisted Death Care Plan form has been signed by the person (their signatory).

#### Prescribing, preparing and dispensing the assisted dying substance

- 644. The law will provide that the Assisted Dying Authorised Drug Regimen will be approved by the Committee during the implementation phase and prior to the commencement of the Jersey Assisted Dying Service [to be detailed in Commencement law drafting instructions, to follow]. The Authorised Drug Regimen will set out the **combination of** drugs/medications used for the purpose of causing the person's death (the "assisted dying substance")
- 645. The authorised drugs regimen may include substances governed by the Medicines (Jersey) Law 1995 and any associated Orders or Regulations / or controlled substances listed in schedule 2 of the Misuse of Drugs (Jersey) Law 1978 and any associated Orders or Regulations.
- 646. The majority of drugs used for the purpose of assisted dying in other jurisdictions are either commonly prescribed or are controlled drugs that are currently used in Jersey for other purposes and at different dosages.
- 647. For the purpose of assisted dying, however, the drugs used would likely involve unlicensed (or 'off-label') prescribing, meaning that the person prescribing the medicine intends to use it in a different way than that stated in its licence. This is because the drugs have not undergone clinical trials for the purpose of bringing about a person's death. 'Off label prescribing' is a recognised practice in other areas of healthcare. If a professional wants to prescribe an unlicensed medicine, or a licensed

medicine off-label, they must follow their professional guidance (for example the General Medical Council's good medical practice guidelines). These guidelines include:

- giving information about the treatment (in this case, it is not a treatment as the drugs will not treat a person but will bring about a person's death); and
- discussing the possible harms and any possible complications that may arise so that the person gives consent to proceed, that consent will be informed
- 648. This informed consent will be discussed at length with the Administering Practitioner, when completing Assisted Death Care Plan.<sup>55</sup>
- 649. Prescribing and Dispensing Guidance will be developed by the Committee. The guidance will set out how the substance will be prescribed, prepared and dispensed in such a way as to ensure:
  - a. a minimal number of individuals handle the substance
  - b. there is a clear chain of command and clear documentation
  - c. the substance is always held securely.
- 650. The law will provide that only the Jersey General Hospital (JGH) Pharmacy will be permitted to compound, store, pack and dispense the assisted dying substance. No other pharmacy will be permitted to do so. For the purposes of clarity, there is no intent to prevent other pharmacies from compounding, storing, packing and dispensing the drugs / medications that make up the assisted dying substance, where those pharmacies are already permitted to do so for other purposes.
- 651. All Pharmacy Professionals involved in the preparation of the substance must be registered with the Jersey Assisted Dying Service.
- 652. All other JGH pharmacy staff have the right to refuse to support the Pharmacy Professionals to prepare and dispense the assisted dying substance.
- 653. The law will allow for any registered assisted dying practitioner who is registered, with the Jersey Care Commission as doctor or an independent prescriber (for example a Nurse Independent Prescriber) to prescribe the assisted dying substance.
- 654. The Prescribing and Dispensing Guidance will set out that:
  - a. the Administering Practitioner will prescribe the substance in most instances.
     Where it is not possible for the Administering Practitioner to prescribe the substance, for example if the Administering Practitioner is a Registered Nurse

<sup>&</sup>lt;sup>55</sup> Information for the public on medicines | Making decisions about your care | NICE and the public | NICE Communities | About | NICE

who is not registered as an independent prescriber, another involved practitioner will prescribe the substance (most usually the Coordinating Doctor). The JGH Pharmacy will hold a list of registered assisted dying practitioners who are also independent prescribing professionals

- b. the prescriber (whether that is the Administering Practitioner or another involved professional) should, wherever possible, provide the JGH Hospital Pharmacy with a copy of the prescription at least 48 hours prior to the planned date for the assisted death.
- 655. The law will set out that the Pharmacy Professional must only dispense the substance to the Administering Practitioner or other Assisted Dying Practitioner. This will allow flexibility for another Assisted Dying Practitioner who is acting as an administration witness to collect the substance, with the same safeguards in place for example they will have undertaken the mandatory assisted dying practitioner training and will be required to complete and sign the Assisted Dying Substance Dispensing form (see paragraph below).
- 656. This can either take place at the JGH Pharmacy or they may deliver to substance to the Administering Practitioner, for example, at the approved location of the assisted death. (The Guidance will state that where the assisted dying substance is to be delivered to a location, this should be agreed in advance)
- 657. When the substance is dispensed, both the Pharmacy Professional (e.g., usually the Pharmacist) and the person collecting the substance (e.g., usually the Administering Practitioner) must complete and sign the Assisted Dying Substance Dispensing form.
- 658. The Assisted Dying Substance Dispensing form will be such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 659. The law will provide that the form must record details of the assisted dying substance and administering products (for example the IV kit) that are dispensed.
- 660. In summary, the Pharmacy Professional(s) who are given the prescription for the person are authorised to:
  - a. possess the prescribed substance for the purpose of preparing it and supplying it to the administering practitioner for the patient; and
  - b. prepare the prescribed substance; and
  - c. supply the prescribed substance to the Administering Practitioner
- 661. In summary, the Administering Practitioner, or other Assisted Dying Practitioner acting at the request of the Administering Practitioner is authorised to:
  - a. receive the prescribed substance from the Pharmacy Professional; and

- b. possess the prescribed substance for the purpose of preparing it and the Administering Practitioner administering it to the person / supporting the person to self-administer; and
- c. prepare the prescribed substance, or direct another suitably qualified health and care professional to do so
- 662. The law will set out that the Administering Practitioner must appropriately dispose of any unused assisted dying substance after the planned assisted death (whether or not the assisted death takes place). The disposal may take place on site (for example if the assisted death took place in JGH or in care facility with appropriate disposal facilities) or returned to the JGH Pharmacy, if on-site disposal is not available. Disposal may be:
  - a. following an assisted death (in the event there is some substance left), or
  - b. if the substance was dispensed but the person does not go through with the assisted death.
- 663. The law will set out that the disposal must be in accordance with specific procedures for the disposal of any controlled drugs including Article 31 of Misuse of Drugs (General Provisions) (Jersey) Order 2009 and any other legislation or professional guidance, the details of which will be outlined in the Assisted Dying Substance Administration Guidance (see Step 7 assisted death delivery below).

# Step 7: Assisted death delivery

- 664. A Step Transition form is not required to move from Step 6 to Step 7, the Assisted Death Care Plan form demonstrates the wish of the person to move to Step 7.
- 665. The Administering Practitioner will arrive at the approved location, on the planned date and time to:
  - a. undertake the Final Review, and
  - b. administer the assisted dying substance / support self-administration of the substance where the person gives final consent (or has a Waiver of Confirmation of Final Consent in place)
- 666. The law will provide that the Administering Practitioner must be accompanied by an administration witness who:
  - a. will witness the preparation and administration / self-administration of the substance
  - b. will check and confirm the accuracy of the information entered in the Post-Assisted Death Administration form by the Administering Practitioner

- c. may provide practical and emotional support to the person and any family / friends who are present
- d. may provide clinical support, in line with their training and competencies, under the direction of the Administering Practitioner, for example, setting up IV tubes and preparing the substance.
- 667. The administration witness will be:
  - a. an assisted dying practitioner (for example a registered nurse from the MDT), or
  - b. where the assisted death is to take place in the Jersey General Hospital, or an adult care home service regulated by the Jersey Care Commission under the Regulation of Care (Jersey) Law 2014, a doctor or registered nurse who works the hospital or care home who does not object to acting at the administration witness (i.e., they are not exercising their right to refuse).
- 668. The law will provide that on arrival the Administering Practitioner must review the Assisted Death Care Plan in order to check that the arrangements accord with the details on the plan, and if they do not, to record any changes on the plan. It is entirely possible that the arrangements may have changed between the development of the plan and the day of the assisted death, for example, the family members present at the death may differ from those originally envisaged.
- 669. The Administering Practitioner must also:
  - a. re-confirm the roles and responsibilities of all present
  - b. re-confirm the method and mode of the assisted death
  - c. reconfirm the consents are in place, for example a Waiver of Final Confirmation of Consent and an ADRT/ DNACPR. Because it is important that they are clear about this information before proceeding.
- 670. The law will provide that the Administering Practitioner must carry out the Final Review, immediately prior to the administration of the substance.

### Final Review

- 671. The law will set out that during the Final Review the Administering Practitioner must, in first instance, confirm the person:
  - a. has capacity to make an assisted dying decision or
  - b. had made a declaration of Waiver of Final Confirmation of Consent.

Has capacity

- 672. If the Administering Practitioner determines that the person has capacity, the Administering Practitioner must then determine whether the person continues to have a voluntary, clear, settled and informed wish to proceed.
- 673. If the person does have capacity, the Administering Practitioner must then confirm if the person is giving final consent to the administration of the substance / to being supported to administer the substance. If final consent is provided, the process may proceed.
- 674. [If the person does have capacity, the Waiver of final Confirmation of Consent will be set aside (i.e. it does not take precedence over the person's views on that day, and the person must provide their consent during the Final Review for the assisted death to proceed.)]
- 675. For the purpose of clarity, when a person gives final consent, they are making a decision to have an assisted death. They must, therefore, have capacity to make that decision (See: section on *Decision-making capacity criteria*)
- 676. If the Administering Practitioner determines that the person does not a voluntary, clear, settled and informed wish to proceed, the process must stop. The Administering Practitioner must:
  - a. inform the person the process has stopped and the reason why the process has stopped
  - b. must record the fact that process has stopped on the Final Consent and Review Form
  - c. must the inform the person that they may choose to appeal to the Royal Court
  - d. must notify the Coordinating Doctor (if the Administering Practitioner is not also the Coordinating Doctor)
- 677. The process cannot restart after the Final review, having been stopped, unless after appeal. There is no second opinion at this stage.

### Does not have capacity - no Waiver of Final Confirmation of Consent

- 678. If the Administering Practitioner determines that the person does not have capacity to give final consent, and there is no Waiver of Final Confirmation of Consent, the Administering Practitioner must determine whether:
  - a. the process must be postponed, on the grounds that the Administering Practitioner is of the opinion that the person's capacity may be fluctuating
  - b. the process must stop, on the grounds that the Administering Practitioner is of the opinion that the person has lost the capacity to make an assisted dying decision

- 679. The Administering Practitioner must inform the person the process has been postponed or stopped and the reason why (to the extent that they may understand the information provided to them)
- 680. The provision for postponement in these circumstances takes account of the fact that the person's capacity may be fluctuating as a result of their illness or the associated medication.
- 681. If the process is postponed, having postponed the process, the Administering Practitioner will, having updated the Assisted Death Care Plan, return on new date / time to repeat the final review process. And, at that point, if the person is found to have capacity and all other associated requirements are met, they may proceed to practitioner administration / self-administration of the substance (the Administering Practitioner may re-assess the person's capacity or make arrangements for a supporting assessment / opinion of the person's capacity by a relevant specialist.
- 682. If the process is stopped, the Administering Practitioner must:
  - a. record that the process has stopped on the Final Consent and Review form
  - b. inform the person that they may choose to appeal to the Royal Court
- 606. The Administering Practitioner will also notify the Coordinating Doctor (if the Administering Practitioner is not also the Coordinating Doctor)
- 607. The process cannot restart after the Final review, having been stopped, unless after appeal. There is no second opinion at this stage.

Does not have capacity - Waiver of Final Confirmation of Consent in place

- 683. If the Administering Practitioner determines that the person does not have capacity but there is a Waiver of Final Confirmation of Consent, the proceed may proceed and there is no requirement for:
  - a. the person to give final consent, or
  - b. for the Administering Practitioner determine if their wish is voluntary, clear, settled and informed (subject to refusal / resistance caveat below)
- 684. As set out in above, where the person has lost capacity and there is a Waiver of Final Confirmation of Consent, the Administering Practitioner will administer the substance, as distinct from supporting self-administration even where the Assisted Death Care Plan records the person's wish to self-administer the substance. This will require the necessary preparations, for example, the insertion of an IV line.

### Final Consent and Review Form

- 685. The law will set out that the Administering Practitioner must record details of the Final Review and make a signed declaration on the Final Consent and Review form to confirm:
  - they are satisfied to the best of their knowledge that the person's assisted dying request has been assessed and approved in accordance with the law
  - that they, the Administering Practitioner has undertaken a final review, and are satisfied that:
    - the person has capacity and continues to have a voluntary, clear, settled and informed wish to proceed, or
    - the person does not have capacity but has previously made a Waiver of Final Confirmation of Consent
  - that they, the Administering Practitioner, has given due consideration to the arrangements set out on person's Assisted Death Care Plan, and,
  - that they, the Administering Practitioner are now satisfied that they may proceed to administering the substance / supporting self-administration of the substance
  - Or if they are not satisfied with all the above, they must sign the Final Consent and Review form to confirm that the process has stopped and the reasons for this.

The Administering Practitioner will Final Consent and Review form will be such form at the Committee decides and will include the information/particulars that is:

- a. provided for in the law
- b. prescribed by Order of the Minister
- c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult.
- 686. Copies of the Final Consent and Review form must be submitted to the Assisted Dying Review Panel, by the Administering Practitioner, along with all other relevant forms and documentation from the person's request, assessment, approval, planning and provision of the assisted death, and this must be done within 2 working days following the person's death, with the day after the death being 'day 1'.

### Preparation of the assisted dying substance prior to administration

687. The law will provide that the Administering Practitioner, or another suitably qualified person under the direction of the Administering Practitioner may proceed to prepare for administration of the substance (for example, inserting IV lines; preparing the substance itself) prior to completion of the Final Review. However, administration of the substance / providing the substance for self-administration, must not take place until after the Final Review has been completed.

- 688. If the Administering Practitioner determines that a person who does not have capacity is demonstrating refusal or resistance to the necessary preparations (for example, the insertion of an IV line) or the administration of the substance (for example, after insertion of the IV line when the Administering Practitioner informs them that substance administration is to commence) the Administering Practitioner should not proceed even though a Waiver of Final Confirmation of Consent in place.
- 689. The Administering Practitioner must then determine whether:
  - the process must be postponed, on the grounds that the Administering Practitioner is of the opinion that the person's refusal or resistance may arise from fluctuating capacity (i.e., they may, on a different day/time, wish to proceed with no signs of refusal or resistance)
  - b. the process must stop, on the grounds that the Administering Practitioner is of the opinion that the person's refusal or resistance is an indication that they do not wish to proceed at all.
- 690. In making their decision, the Administering Practitioner will consult family / loved ones who are present.
- 691. The Administering Practitioner must inform the person the process has been postponed or stopped and the reason why (to the extent that they may understand the information provided to them)
- 692. If the process is postponed, having postponed the process, the Administering Practitioner will, having updated the Assisted Death Care Plan, return on new date / time to repeat the final review process. And, at that point, the person may proceed to practitioner administration / self-administration of the substance if there are no signs of refusal or resistance.
- 693. If the process is stopped, the Administering Practitioner must:
  - a. record that the process has stopped on the Final Consent and Review form
  - b. inform the person that they may choose to appeal to the Royal Court (to the extent that the person may understand the information provided to them)

The Administering Practitioner will also notify the Coordinating Doctor (if the Administering Practitioner is not also the Coordinating Doctor)

- 694. If Administering Practitioner believes that a person who has capacity and who has provided final consent is demonstrating refusal or resistance, the Administering Practitioner must establish if they wish to withdraw that consent.
- 695. If they do wish to withdraw consent and the Administering Practitioner must record that on Final Consent and Review Form, and the process will stop.

696. The Assisted Dying Substance Administration Guidance will provide guidance for the Administering Practitioner to determine whether the person is demonstrating refusal or resistance to the administration of the substance.

### Postponement in process post Final Review

- 697. There may be medical or other reasons why the substance is not administered, after the Final Review even when the person is found to have capacity and has decided they wish to proceed to have an assisted death– for example the person may be unwell (vomiting) and unable to self-administer the substance orally, or, may wish not to be unwell (vomiting) during the administration of the substance as this impacts on their engagement with their family at the point of their death.
- 698. In these circumstances, the person may request for the assisted death to be postponed or the Administering Practitioner may decide the assisted death should be postponed, because there is a risk that administration of the substance may result in medical complications.
- 699. If the process is to be postponed, following the Final Review, the Final Consent and Review Form must still be completed, and the reasons for postponing the process must be recorded
- 700. No person other than the person may request that the assisted death is postponed.
- 701. If the assisted death is postponed, the Administering Practitioner must update the Assisted Death Care Plan and agree a new planned date/time with the person. On the new date, Step 7 the assisted death delivery must be completed in its entirety i.e. the final review must be repeated, prior to administration of the substance.

### Methods for administration of an assisted death

- 702. When the person has chosen <u>self-administration</u>, the law will set out that the Administering Practitioner:
  - a. must prepare the substance or direct a suitably qualified person to do so, which may include:
    - i. the administration witness
    - ii. another assisted dying practitioner, who is suitably qualified to do so, who is present
    - iii. Or another health and care professional, who is suitably qualified to do so, and is present

(Where the Administering Practitioner directs someone to prepare the substance, the Administering Practitioner must witness that person preparing the substance)

- b. must direct the person (and any family member who is assisting the person) as to how the substance should be taken. The administration witness or any other person must not provide that direction
- c. must provide the substance to the person
- d. must stay with whilst the person whilst the person takes the substance
- e. must either stay with the person or nearby the person as the person wishes until the person dies. The Administering Practitioner does not need to be in the same room, but they must remain close by. Note: this level of detail does not need to be determined in advance of the Assisted Death Care Plan as it is highly possible that the person will not know in advance what they wish but it must be record on the Post-death Administration form.
- f. check and confirm death as soon as practicably possible, remove:
  - i. any unused substance, and
  - any items related to the administration of the substance, such as IV lines or feeding tubes, and remove these for safe disposal, or return to the General Hospital Pharmacy
- 703. The law will provide that where the person has chosen to self-administer the substance, a family member or loved one may support them in the process, for example supporting the person to bring the cup to their lips, but this may only be done under the direction and observation of the Administering Practitioner (i.e., The Administering Practitioner must stay until the substance has been administered to ensure there is not risk of interference but, post administration, may then leave the room providing they remain close by)
- 704. The Assisted Dying Substance Administration Guidance will provide detailed information on supporting self-administer, will also be covered within the assisted dying training modules.
- 705. The law will set out that the administration witness must witness:
  - a. the Administering Practitioner preparing the substance (if the witness has not been directed by the Administering Practitioner to prepare the substance)
  - b. the Administering Practitioner providing the substance to the person
  - c. the person taking the substance either with, or without the support of their family

- 706. When a person has chosen <u>practitioner administration</u>, the law will set out that the Administering Practitioner must:
  - a. must prepare the substance or direct suitably qualified person to do so, which may include:
    - the administration witness
    - another assisted dying practitioner, who is suitably qualified to do so, who is present
    - Or another health and care professional, who is suitably qualified to do so, and is present

(Where the Administering Practitioner directs someone to prepare the substance, the Administering Practitioner must witness that person preparing the substance)

- b. administer the substance (they cannot direct the administration witness or any other person to do so)
- c. stay with or nearby the person, as the person wishes, until the person dies (they do not have to be in the same room, but they must remain close by) Note: this level of detail does not need to be determined in advance of the Assisted Death Care Plan as it is highly possible that the person will know in advance what they wish but it must be record on the Post-death Administration form.
- d. check and confirm the death
- e. As soon as practicably possible, remove:
  - i. any unused substance, and
  - ii. any items related to the substance, such as IV lines or feeding tubes, and remove these for safe disposal, or return to the General Hospital Pharmacy.
- 707. The law will provide that, whilst other suitably qualified professionals, which may be the administration witness or any other doctor or registered nurse who does not wish to invoke their right to refuse, may assist the Administering Practitioner with the process, for example, setting up IV tubes and preparing the substance, the only persons authorised in law to administer the substance will be:
  - a. the Administering Practitioner, or
  - b. the person, with or without the assistance of a loved one.
- 708. The law will set out that the administration witness must witness:
  - a. the Administering Practitioner preparing the substance (if the witness has not been directed by the Administering Practitioner to prepare the substance)
  - b. the Administering Practitioner administering the substance to the person

Complications with administration of the assisted dying substance

- 709. The law will provide that:
  - a. the Assisted Dying Substance Administration Guidance must include detailed protocols to cover the occurrence of a medical complication
  - b. the assisted dying training programme must also include a module on occurrence of a medical complication
- 710. Administration complications could include the person taking longer to die than expected or issues with the administration of the substance (for example regurgitation and vomiting, or seizure).
- 711. In most cases it is anticipated that the person will have:
  - made an advance decision to refuse treatment which would prevent medical staff from attempting resuscitation
  - b. provided Confirmation of Consent to Proceed, which would permit the Administering Practitioner to administer the assisted dying substance via IV if oral administration fails or medical complications that prevent the completion of the assisted death, including regurgitation and vomiting, or seizure or there is delayed effectiveness of oral medication, where the person has not died within 60 minutes of taking the substance orally.
- 712. Where there are complications with oral administration of the substance, the Guidance will set out that the Administering Practitioner:
  - a. may move to IV administration:
    - with consent of the person if they still have decision-making capacity at that point, or
    - where there is a Consent to Proceed in place, even where the person has lost decision making capacity
  - b. will not be able to move to IV administration where the person has lost capacity and there is no consent to proceed in place. In these circumstances the Administering Practitioner can do no more than take appropriate measure to help ensure the person is comfortable, for example administering oxygen. It is possible, albeit extremely unlikely, that the person may require transfer to hospital in these circumstances.
- 713. In the highly unlikely event that there is also no Advanced Decision to Refuse Treatment in place, and the person has lost the capacity to refuse treatment at this

point in time, the Administering Practitioner (and/or hospital staff) <u>may</u> need to attempt life sustaining measures but only if it were deemed appropriate to do so (i.e. the life sustaining measures is likely to be successful and it would not cause additional harm to the person). The Administering Practitioner (and/or hospital staff) would also need to consider if it were in the person's best interest which would generally be considered unlikely given that it is directly contradicts their assisted dying request.

# Step 8: After an assisted death

- 714. A Post-Assisted Death Administration form will be in such form at the Committee decides and will include the information/particulars that is:
  - a. provided for in the law
  - b. prescribed by Order of the Minister
  - c. that the Committee determines it should contain, having consulted the Minister and anyone the Minister deems appropriate to consult
- 715. The law will provide that the Post-Assisted Death Administration form must be:
  - a. completed the Administering Practitioner
  - b. signed and dated by the Administering Practitioner and the Administration Witness, who must confirm (to the best of their ability) if all the details entered into the form by the Administering Practitioner are correct
- 716. The law should provide that, after the assisted death, the Administering Practitioner must:
  - a. complete the Post-Assisted Death Administration form as soon as practicably possible after the death, and then make arrangements to submit a signed and completed copy of the Post-Assisted Death Administration form to the Assisted Dying Review Panel. It must be submitted within 2 working days of the death, with day 1 being the first working day after the assisted death.
  - b. notify / make arrangements to notify the ADRMP of the death, within 2 working days of the death, and provide the ADRMP a signed and dated copy of the Final Consent and Review form and a signed and dated copy of the Post-Assisted Death Administration form
  - c. notify / make arrangements to notify the Superintendent Registrar that an assisted death has occurred. This notification must be within two days given that the Marriage and Civil Status (Jersey) Law 2001 requires a relevant registrar to

be informed of a death within 5 days (See section below: *Amendments to other legislation*)

- 717. The notification to the Superintendent Registrar must contain the following particulars:
  - a. name of the person
  - b. date of birth of the person
  - c. date of death of the person
  - d. parish in which the death took place.
- 718. In addition to the Post-Assisted Death Administration form required under the Assisted dying law, a Medical Certificate of Fact and Cause of Death ("MCFCD") must also be completed in the same way as all other deaths in Jersey, as required under Article 64 of the Marriage and Civil Status (Jersey) Law 2011 ("the 2001 Law"). Note, the ADRMP training module will support accuracy and consistency in the completion of MCFCDs for all assisted deaths. As this is in accordance with the arrangements of the 2011 Marriage and Civil Status Law no further provisions need to be made in relation to completion of the MCFCD in the assisted dying law.
- 719. All assisted deaths will be certified by ADRMP who will complete the MCFCD. As set out above (See Step 6-Assisted Death Care Planning), the Administering Practitioner must ensure the ADRMP attends the person within the 14 days period prior to the assisted death taking place in order that they are qualified to certify that death in line with Article 64 of Marriage and Civil Status (Jersey) Law 2001.
- 720. The law will also set out that, where a person is to be cremated after the assisted death, the Registered Medical Practitioner (RMP) who completes the certificate of application for cremation (as required by the Cremation (Jersey) Law 1953 and the Cremation (Jersey) Regulations 1961) must not be either a relative or partner (to include spouse, civil partner or cohabiting partner) of either the Administering Practitioner in the case of an assisted death, or the ADRMP who completed the MCFCD. For clarity the doctor who completes the certificate of application for cremation may be an ADRMP or an RMP.

# 8. Regulation and oversight

This section outlines matters related to the regulation and oversight of the Jersey Assisted Dying Service.

### Post-death review

- 721. The law will provide that:
  - a. a post-death review must be undertaken after each assisted death. It is an administrative review
  - b. the post-death review must be undertaken by the Assisted Dying Review Panel ("the Panel").
    - in accordance with any processes provided for by Order of the Minister
    - in accordance with any timeframes provided for by Order of the Minister

### Note to law drafting officer

It is envisaged the processes and timeframes will be provided for in Order, as distinct from Regulations, it is recognised that both may be subject to change once the operational realities are better known. This is, however, a matter for the law drafting officer to provide advice on.

- c. the purpose of the post-death review is for the Panel to determine whether, in the case of each assisted death, there was proper adherence to the legislation and guidance
- d. the Panel must report to the Committee its determination and any associated findings
- e. the Panel may also make recommendations that the Panel considers necessary to addressing its finding. In the even the Panel does make recommendations it must set out the reasons for making those recommendations.
- f. the Committee must give due consideration to the Panel's determination, findings and recommendations. It may adopt or reject any of the recommendations, or take any alternative course of action that the Committee believes to be best course of action

- g. the Committee, having considered the Panel's finding and determined what, if any action to take, will provide a copy of the Panel's report to the Jersey Care Commission with details of any action to be taken.
- 722. It should be noted that even where the Panel determines that the assisted death accorded with legislation and guidance, the Panel may, nevertheless identify potential process improvements and make associated recommendations.
- 723. In undertaking a post-death review the Panel:
  - a. must review all the documents that form part of the Assisted Dying Person Record, including any supporting documents
  - b. must review any available relevant documentation related to an appeal (in the event of an appeal)
  - c. may request, from the person listed below, and any other person that the Panel deems relevant, any other information the Panel deems relevant to the post-death review:
    - any involved professional
    - the Care Navigator
    - any assisted dying practitioner
    - any professional who provided a supporting assessment / opinion;
    - the Viscount or the Medical Examiner [should the role of Medical Examiner be established in law]
- 724. The persons listed above will be asked to provide the information requested by the Panel to the Panel in manner (in person and / or writing) and timeframe requested by the Panel, where that information is required for the purposes of a post-death review and where the appropriate information sharing consents are in place.

# Other reviews

- 725. The law will further provide that the Panel will work to identify, through ongoing analysis of post-death reviews that have be undertaken, matters related to:
  - a. the assisted dying process, and the delivery of that process, which the Panel believes may require improvement / change
  - b. the actions of an assisted dying practitioner / assisted dying practitioners which the Panel believes may require further investigation.
- 726. These *process reviews* will be undertaken by the Panel as and when the Panel deems it practicable to undertake such a review (the Panel cannot, for example, undertake meaningful analysis of the actions of an assisted dying practitioner above and beyond the analysis undertaken as part of post-death review- if that practitioner has only been involved in one assisted death.
- 727. The Panel will undertake reviews of assisted death requests that did not progress to an assisted death when directed to do so by the Committee (whether or not on the request of the Minister). The Committee may direct the Panel to undertake *request*

*reviews*, as the Committee deems necessary for it to be assured of matters related to the delivery of the assisted dying process, and compliance with law and guidance.

- 728. The Panel will report to the Committee the findings of any *process reviews* or *request reviews* that is undertakes, and may make any associated recommendations, setting out the reasons for making those recommendations.
- 729. In the event Panel does make recommendations that arrangements for responding to those recommendations will be as per post-death reviews (See above)

### Recommendations

Examples of the types of recommendations the Panel could make include:

- potential safety, quality improvements or process changes (including proposed changes to guidance, practice, forms or training)
- referring matters to a relevant person or body, for example, HCS as the employer / contracting body for involved professionals, the Coroner, the States of Jersey Police, the Superintendent Registrar, the relevant professional lead (for example, the Chief Pharmacist or Chief Nurse; Safeguarding Partnership Board)
- consider of whether further investigation may be required by HCS as the employer / contracting body for involved professionals. This could include, for example, whether an assisted dying practitioner is suspended from the Assisted Dying Register pending a full investigation of their practice and whether this investigation is undertaken by HCS as the employer / contracting body for involved professionals, the JCC, a relevant UK professional regulatory body or another relevant body).

This list of examples is not exhaustive

# Terms of reference

730. The law will provide that:

- a. the Committee must develop terms of reference for the Panel, and the Panel must operate in accordance with its terms of reference
  - Prior to presenting those terms of reference to the Minister, the Committee must consult the Jersey Care Commission and any other entities or persons that the Committee deems are relevant to consult
- b. the Minister must adopt those terms of reference, and amendments proposed by the Committee, by ministerial decision

- c. the terms of reference must have regard to matters provided for in law and any matters related to the undertaking of post-death reviews as prescribed by Order of the Minister. The Law Drafting Officer is asked to make provision for the making of such an Order.
- 731. The law will further provide that the terms of reference must set out matters related to:
  - a. arrangements for the appointment and removal of Panel membership, including the maximum and minimum number of members
  - b. any processes and procedure the Committee deems necessary for the Panel to deliver its functions

# Panel members

- 732. The law will provide that members of the Panel:
  - a. must be appointed by the Minister, on the recommendation of the Committee. For the purposes of clarity, the Minister is not required to appoint a person recommended by the Committee
  - b. must have expertise and knowledge across of a range of relevant disciplines, with those relevant disciplines being set out in the terms of reference to be adopted by the Minster
  - c. may include non-GoJ employees and Government of Jersey employees, providing the Committee have determined that this does not represent a conflict
  - d. may be remunerated as the Minister deems appropriate, unless the Panel member is a Government of Jersey employee

# Note: Detail of matters to be provided for by Order

As set out above, post-death reviews must be undertaken by the Assisted Dying Review Panel ("the Panel").

- in accordance with the processes provided for by Order of the Minister
- in accordance with the timeframes provided for by Order of the Minister

### Processes

The processes to be provided for in Order are:

When conducting a post-death review the Panel will undertake an initial review of the Assisted Dying Person Record and any available relevant documentation related to an appeal (in the event of an appeal)

Having undertaken the initial review, the Panel must determine whether, in their opinion:

a. there was adherence to the legislation and guidance; or

- b. the legislation and guidance were not adhered to
- 733. Having determined whether the legislation and guidance was, or was not adhered to, the Panel will report its determination and any associated recommendations to the Committee
- 734. If, having undertaken an initial review the Panel is unable to form an opinion they must determine what additional information is required for them to make a determination, and must request that this additional information is provided to them.
- 735. The Panel may request that the additional information to be provided in writing and / or in person, which may include attendance at a Panel meeting by any of the following:
  - a. any involved professional, and / or
  - b. the Care Navigator and / or
  - c. assisted dying practitioner and/ or
  - d. anyone who provided a professional supporting assessment / opinion.
- 736. The Panel must specify, in writing to the professional, the information that is required and the timeframe in which it is required.
- 737. Whilst a person who is engaged as assisted dying practitioner can be required as a condition of contract to provide information to the Panel (providing the necessary information sharing consents are in place), the Panel does not have powers to compel others to provide information (for example, professional who provided supporting assessments who are not GoJ employees). It may, therefore, be unable to acquire all the information it needs to make a determination.
- 738. Having received that additional information, the Panel must then make a determination as to whether law and guidance were, or were not, adhered to, and will report its determination and any associated recommendations to the Committee.
- 739. If the Panel is still unable to make a determination, it must report to the Committee the matters which it believes require further examination or investigation.

# Timeframe

- 740. The Order will provide that a post-death review shall be completed, and the Panel report submitted to the Committee:
  - a. within 6 weeks of the assisted death, or
  - b. within 12 weeks where the Panel requires additional information to be provided

- 741. Where the Panel is unable to report to the Committee within this timeframe it must notify the Committee of the reasons of the delay and the Committee must determine the action to be taken. Actions may include, but are not limited to:
  - a. provision of a longer timeframe for the post-death review
  - b. provision of additional resource to facilitate completion of the review
  - c. notification to the Minister
  - d. consideration of whether, pending completion of the review
  - e. matters that should be referred to a relevant person or body,
  - f. further investigation should be commenced
  - g. an assisted dying practitioner should be suspended from the Assisted Dying Register

# Note: Additional detail of matters to be provided for in the Terms of reference

### Relevant disciplines

- 742. It is envisaged that the relevant disciplines for Panel members, to be set out in the terms of reference will include:
  - a. legal expertise
  - b. end-of-life care specialists
  - c. medical ethicists
  - d. social care practitioners (including care for older people and people with disabilities)
  - e. medical practitioners with expertise in the types of terminal illness that give rise to assisted dying requests, and
  - f. people with expertise in clinical service governance and safety.

# **Registration and inspection by the Jersey Care Commission**

- 743. The law will provide that the Assisted Dying Service will be regulated and inspected by the Jersey Care Commission ("JCC"). This will require the Regulation of Care Law (Jersey) Law 2014 (the "2014 Law") to be amended to extend the Jersey Care Commission's remit to the Jersey Assisted Dying Service.
- 744. The 2014 Law provides a legislative framework for the independent regulation of health and social care in Jersey. It is underpinned by the Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018 (the "2018 Regulations") which provides a detailed set of requirements that all regulated services must adhere to.<sup>56</sup>

<sup>&</sup>lt;sup>56</sup> Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018

- 745. Schedule 1 to the 2014 Law will be amended to include the Jersey Assisted Dying Service as a defined regulated activity. Transitional arrangements will provide that the Jersey Assisted Dying Service may not operate until its provider and manager have registered with the JCC. To register the service, the JCC will require HCS to submit all the information the JCC deems necessary. This may include the JCC undertaking pre-registration visits (for example, to HCS pharmacy department to look at dispensing arrangements).
- 746. Regulations should be introduced under Article 3(7)(a) of the 2014 Law which set out that the registered provider of the Jersey Assisted Dying Service will be the Chief Officer of the Health and Community Services Department or equivalent, who will have responsibility for ensuring that the Jersey Assisted Dying Service adheres to statutory requirements set out under the 2018 Regulations. In addition, the operational manager of the service will be required to register with the JCC (a decision as to who is designated as the operational manager will be determined at the point at which the assisted dying law is approved and HCS commences service development).
- 747. The registration of the providers and managers of regulated activities is fundamental to the regulatory regime established by the 2014 Law. The regulatory regime requires the JCC to consider whether providers and managers, and the services they run are fit to be registered. Where a provider, manager or service is not fit or does not meet the regulatory standards required then this can be dealt with by the JCC applying conditions to registration, or potentially suspending or cancelling a service's registration. Providing a regulated activity without registration is an offence under Article 3(4) of the 2014 Law. A provider who commits this offence is liable to imprisonment for a term of 12 months and to a fine.
- 748. For clarity, no condition of registration imposed by JCC should be capable of overriding or contradicting any of the responsibilities or requirements placed on the Jersey Assisted Dying Service under the assisted dying law. Subject to Law drafting officers' advice, it may be necessary to include a provision under the Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018, to put this beyond doubt.
- 749. Once registered with the JCC, Jersey Assisted Dying Service may commence operations. The Assisted Dying Assurance and Delivery Committee and the Service's registered manager must ensure that the Service acts in compliance with the statutory requirements which apply to all regulated health and social care services under Regulations 2 to 27 of the 2018 Regulations. This is in addition to the requirements placed on the Committee, via the Assisted Dying Law, to ensure compliance with the requirements under the Assisted Dying Law (see Section: Assisted Dying Assurance and Delivery Committee (and its functions))
- 750. In addition, a new Regulation is required which is specific to the Jersey Assisted Dying Service. This should provide that the Service is required to discharge its statutory functions in accordance with the Law. A similar provision is provided in respect of social work services for children and young people under Regulation 77(2) of the 2018 Regulations. This is important as it will enable the JCC to regulate the Service fully,

ensuring that it is compliant with all its statutory responsibilities as well as the general requirements placed on all services under Regulations 2 to 27 of the 2018 Regulations.

- 751. Furthermore, Regulation 29 will need to be amended to state that the JCC cannot stipulate that the assisted dying service must restrict its activities to particular categories of service user or particular age groups. These decisions will be for the Assembly.
- 752. Regulation 80 of the 2018 Regulations should be amended to ensure that the JCC must inspect the Jersey Assisted Dying Service at least once every 12 months to monitor and enforce compliance with both the 2018 Regulations and the new Assisted Dying Legislation. While the JCC must inspect the Service at least once per year, it may decide to inspect the service at any other time on either an announced or an unannounced basis. Article 26 of the 2014 Law provides the JCC with the power to enter any premises provided in connection with the provision of a regulated activity with or without the consent of registered providers or managers (excluding private dwellings, where consent is required).
- 753. In anticipation of the amendments to the 2014 Law coming into force, the JCC will develop, consult on and publish detailed standards setting out what providers must do to meet the requirements of the 2018 Regulations. This is provided for under Article 15 of the 2014 Law. These standards will provide the Jersey Assisted Dying Service with clear inspection guidance and will supplement the 2018 Regulations with further, specific requirements for the Service on how the JCC expects it to demonstrate compliance with the Law.

# Acting on findings arising from inspections or from the Assisted Dying Review Panel

- 754. If the JCC finds that the Jersey Assisted Dying Service is failing to meet any of the requirements set out under the 2018 Regulations or its other statutory responsibilities, the JCC will take action in accordance with its existing escalation and enforcement policy and, in the first instance, is likely to issue the Service with an improvement notice.<sup>57</sup> Under Regulation 82(2) of the 2018 Regulations, this is a notice:
  - a. informing the registered person that these Regulations have been contravened;
  - b. specifying the time frame within which remedial action must be taken; and
  - c. explaining the consequences of a failure to take that remedial action.
- 755. Where the Service contravenes a requirement and fails to comply with an improvement notice, the JCC may refer this fact and relevant prosecution information to the Attorney General to decide whether to prosecute the registered provider and/or the registered manager of the Jersey Assisted Dying Service. A registered person who

<sup>&</sup>lt;sup>57</sup> https://carecommission.je/wp-content/uploads/2022/03/Escalation-and-Enforcement-Policy-002.pdf

is found to have committed an offence is, under Regulation 82(5), liable to a fine of  $\pounds$ 50,000 for each breach of the Regulations.

- 756. Where the JCC finds that the registered manager of the Jersey Assisted Dying Service is not a fit person or has failed to comply with conditions or requirements imposed upon them, the JCC has the power to suspend their registration under Article 19 of the 2014 Law. The JCC may also cancel the manager's registration under Article 20(2) of the 2014 Law.
- 757. The ultimate sanction against services regulated under the 2014 Law is the cancellation of a service provider's registration with the JCC under Article 20 or Article 21 of the 2014 Law. This would, in effect, shut down the regulated service.
- 758. Article 22 of the Regulation of Care (Jersey) Law 2014 effectively provides that the JCC may cancel the registration of a service provider who fails to comply with conditions imposed on them by the JCC unless that service is an 'essential' service (i.e. a service for which a Minister is the sole provider). As the Jersey Assisted Dying Service would meet this definition of an essential service, the JCC could not cancel its registration but could escalate its concerns via a report to the Council of Ministers.
- 759. However, given the special nature of the Jersey Assisted Dying Service, Article 22(1) of the 2014 Law will be amended to provide that, even though the Minister will be the sole provider of the Service, it will fall outside of the definition of an 'essential service'. This will enable the JCC to cancel its registration if the JCC determines that there are grounds to do so.
- 760. To protect those who may have been approved for assisted dying but are yet to have been assisted to die, a new provision is required to ensure that these individuals will be unaffected by the cancellation of the Jersey Assisted Dying Service's registration under Articles 20 or 21 of the 2014 Law. This will establish that the effect of cancellation on the Service will be to prevent it from being able to assess and approve persons making new requests to have an assisted death, but that those with existing approvals may still have an assisted death unless the JCC's grounds for cancellation rest with individual practice of either Coordinating Doctor and/or Independent Assessment Doctor of those specific persons.

# 9. Consequential amendments

This section sets out amendments that will be required to other legislation. Please note that work is still ongoing to identify other consequential amendments that may be required.

### Marriage and Civil Status (Jersey) Law 2001 ("the 2001 Law")

- 761. Due to the specific and infrequent nature of an assisted death (<5% total deaths) is it proposed to limit, in statute, the ability to register an assisted death to only the Superintendent Registrar. This is a similar limitation to provisions that govern other infrequent, intricate or sensitive registrations such as the registration of the birth of an abandoned child, an adoption, or the re-registration of a birth following the grant of an application for a gender recognition certificate. In practice, this limitation will have no effect as currently the Superintendent Registrar holds responsibility for registration for all parishes. However, a parish could serve notice to take back registration at any time. Limiting the registration in this way provides certainty for the process going forward.</p>
- 762. Two articles of the 2001 Law stipulate who can register a death, it is proposed to introduce exemptions in both Article 62(1) and Article 68, so that, in the case of an assisted death registration duties would be limited to the Superintendent Registrar only.
- 763. It is proposed that an assisted death would not have to be reported to the Police or Viscount as a matter of course, other than where the death was not in accordance with, or suspected not to be in accordance, with assisted dying legislation.
- 764. Article 65(c) of the 2001 Law will need to be amended so that the duty placed on a relevant registrar to notify the Viscount of a death which is "believed to be unnatural" is altered so that the 2001 Law does not require the notification to take place where the death is an assisted death.
- 765. Furthermore, the Law will need to make amendment to Article 65(e) of the 2001 Law so that the relevant registrar is not required to notify the Viscount if the death appears to have occurred during a 'medical procedure' provided that death was an assisted death conducted in accordance with assisted dying legislation. Article 65(e) currently sets out:

"Where the relevant registrar is informed of the death of any person he or she shall, as soon as practicable, notify the Viscount of the death if the death is one which appears to the relevant registrar to have occurred during a surgical operation or other medical procedure or before recovery from the effect of an anaesthetic."

Law drafting officers should note that draft Law Drafting Instructions on amendments to the statutory provisions for Death Management, propose that the duty to notify the Viscount, may be amended to be a duty of the Medical Examiner, not the relevant

registrar. Should this be agreed, the assisted dying law should have the flexibility to mirror these changes – i.e. to exempt whoever has the duty notify the Viscount under article 65, when the death is an assisted death. Again, at present it is anticipated that these changes would come into effect by 2026, i.e. before the implementation of assisted dying (c. Summer 2027).

### Inquests and Post-Mortem Examinations (Jersey) Law 1995 ("the 1995 Law")

- 766. Article 2(1)(c) of the 1995 Law will require amendment to clarify that Article 2(1)(c) does not apply to assisted deaths conducted in accordance with assisted dying legislation. The amended Article would exempt all deaths brought about by assisted dying. However, any person would still be able to report a death (including an assisted death) where they have reason to believe that a deceased person died as a result of violence or misadventure, as a result of negligence or misconduct or malpractice on the part of others, or under such circumstances as may require investigation as per Article 2(1) of the current legislation.
- 767. Article 2(4)(a) & (b) of the 1995 Law currently sets out that when someone dies while they are a patient in an establishment approved under the Mental Health (Jersey) Law 2016 (including persons on leave from that establishment), a Children's Home within the meaning of the Children (Jersey) Law 2002 and a home consisting of a care home service, as defined in paragraph 4 of Schedule 1 of the Regulation of Care (Jersey) Law 2014, that the care home manager or the person in charge of the home must immediately notify a police officer of the facts and circumstances relating to the death. The police officer in turn must, as soon as reasonably practicable, notify the Viscount of those facts and circumstances. The draft Law needs to amend this Article to disapply this requirement where an assisted death, conducted in accordance with assisted dying legislation, takes place in a care home service, so that the manager or person in charge is not required to notify a police officer.

# Cremation (Jersey) Regulations 1961 ("the 1961 Regulations")

- 768. Regulation 8 of the 1961 Regulations currently prohibits a medical referee from allowing a cremation where: *"it appears to the medical referee considering an application under Regulation 5, from the cause of death assigned in the medical certificates accompanying the application, that the death has, or might have, resulted from poison".*
- 769. It is necessary to create an exemption for an assisted death, conducted in accordance with assisted dying legislation, from Regulation 8 as some substances that could be used in an assisted death do appear on the Poisons List (Jersey) Order 1986. Therefore, under Regulation 8 as currently enacted the death would appear to the

medical referee to have resulted from poison. The medical referee would then be required to refuse to allow a cremation and to refer the matter to the Viscount.

770. The 1961 Regulations should be amended so that a medical referee is not prohibited from allowing a cremation and not required to refer the matter to the Viscount. Even where the death has resulted from or may have resulted from poison, provided the assisted death was conducted in accordance with assisted dying legislation.

# **10.** Protections for health and care professionals

- 771. It is intended that the law should provide specific protections, in relation to employment for people who participate / intend to participate in assisted dying or who exercise their right to refuse to participate.
- 772. The requirement for such protections was raised by the BMA, following consultation with their members and significant research undertaken by their ethics committee.
- 773. The New Zealand End of Life Choice Act 2019, provides protections for health practitioners who conscientiously object, by placing requirements on employers not to treat a person unfairly because of a conscientious objection to assisted dying.<sup>58</sup>
- 774. Further to this, the Isle of Man's Assisted Dying Bill 2023 passed its third reading in House of Keys in July 2024 and was amended to include protections for persons who either exercise a right to conscientious objection or who choose to participate as a health professional in assisted dying.<sup>59</sup>

Note: the term 'employment' below also refers to a 'contract of service' or equivalent.

# Protections for people who refuse to participate

- 775. The law should provide that a person who exercises their right to refuse to participate must not, as a consequence of exercising that right:
  - a. have their employment terminated; or
  - b. be treated less favourably by their employer in the course of that employment (for example, they should not be overlooked for promotion or training opportunities; required to move role or position in their organisation; be subject to hostile

<sup>&</sup>lt;sup>58</sup> End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 8 Conscientious objection – New Zealand Legislation

<sup>59</sup> Assisted Dying Bill 2023

behaviours; excluded from meetings, projects etc; be denied any benefits of employment to accrue to other employees undertaking the same work – salary, benefit, accommodation etc), or

c. be denied a contract of employment solely on the basis grounds that they have exercised their right to refuse / anticipate exercising their right to refuse.

(Sub-paras a – c above are the 'employment detriments')

776. The person referred to in the above paragraph is a person who has a right to refuse (i.e., the persons described in *Right to Refuse* section of the core instructions.)

777. For the purposes of clarity, the provisions above do not include:

- a. any person, who by dint of being a relevant professional lead is appointed as a member of the Assurance and Oversight Committee. This is because, as set out in *'right to refuse'* section of the core instructions, a person who is a relevant professional lead cannot refuse to be a member of the Committee, as undertaking a governance task related to the general provision of an assisted dying service is not considered to constitute participation in assisted dying
- b. any person appointed as Assisted Dying Review Panel chair or panel member, as above, such a person is undertaking a governance task related to the general provision of an assisted dying.

# Protections for professionals

- 778. The law should provide that a person who undertakes any of the roles or functions below (or anticipates so doing) where those roles / functions related to assisted dying, must not, as a consequence of so doing suffer the employment detriments set out above.
- 779. Roles / functions include:
  - a. assisted dying practitioner
  - b. Care Navigator
  - c. ADRMP
  - d. A health or care professional who refers a person to the Jersey Assisted Dying Service
  - e. A member of the Assurance and Oversight Committee (whether or not they are a relevant professional)
  - f. A member of a Post-death review panel
  - g. A person engaged by the Jersey Care Commission to support the Commission in the delivery of its functions related to the assisted dying
  - h. A professional who provides a professional supporting assessments / opinions

- i. A person who provides communications support
- j. A professional who acts as the administration witness or supports the Administering Practitioner with the preparation of the assisted dying substance
- 780. Law drafting officers are asked to consider whether the proposed protections would best be provided in the assisted dying law (as per New Zealand, and proposed Isle of Man Law) or whether they should be given effect through consequential amendments to the Employment (Jersey) Law 2003.

### Provisions relating to Administrating Practitioners and administration witnesses

- 781. It is understood that some Administering Practitioners, and by extension some people acting as an administration witness, hold differing positions on self-administration of the assisted dying substance which they see as supporting a person to end their own life and practitioner administration of the assisted dying substance which they see as taking the life of another person.
- 782. For the reason the law should provide that a person who is acting as an Administering Practitioner or administration witness should not suffer any detriment if they refuse to administer the substance (support or witness practitioner administration of the substance), as distinct from supporting self-administration (supporting or witnessing self-administration). This does not apply:
  - a. where the Administering Practitioner previously agreed with the person that they, the Administering Practitioner, would administer the substance OR
  - where a person who elected to self-administer the substance, having done so, experienced complications which required intervention by the Administering Practitioner and that intervention may reasonably have included reverting to practitioner administration

### Safe access zones

- 783. A safe access zone is a designated area around premises where certain services are provided where protests and demonstrations and other activities are expressly prohibited. They are intended to protect both professionals and service users from potential harassment and/or abuse. Safe access zone legislation regarding abortion services exists in a number of jurisdictions, including England and Wales, Scotland and Northern Ireland.
- 784. Activities prohibited within a safe access zone, may include for example:
  - a. obstructing or impeding any person accessing, providing, or facilitating the provision of assisted dying services

- b. causing harassment, alarm or distress to any person in connection with a decision to access, provide, or facilitate the provision of assisted dying services
- 785. The law should provide that it will be an offence for a person, within a designated assisted dying safe access zone, to undertake a prohibited act.
- 786. The law should provide for powers to:
  - a. designate areas as assisted dying safe access zone/s, and
  - b. provide for the acts that are prohibited acts, and
  - c. provide the circumstances in which the offence is, or is not committed.
- 787. It is not proposed that:
  - a. any areas are designated as safe access zones on the face of the law, on the basis that:
    - i. decisions as to the location of the Jersey Assisted Dying Service have yet to be taken
    - ii. detailed consultation with premises owners, premises providers, premises users and law enforcement would be required prior to the designation of such zones
  - b. the descriptions or categories of prohibited acts are provided for on the face of the law as these similarly require more detailed consultation
- 788. It is therefore envisaged that the law drafting officer will provide a power for the Assembly to introduced safe access zone provisions by Regulations.
- 789. Designated assisted dying safe access zones could include premises or their access point, and a specific boundary around those premises (e.g.: 150 metres around the premises), where:
  - a. the Assisted Dying Service is located / operates from (for example, a 150metre zone around the entrance to the Jersey Assisted Dying Office, or 150 metre zone around any entrance to the Jersey General Hospital if the Services is located in the hospital)
  - b. assisted dying assessments and meetings are held as part of the assisted dying process
  - c. an assisted death is to be carried out (this could include, for example the home of an individual person)
  - d. assisted dying practitioners work (for example, a GPs surgery if one of the GPs working in that surgery was an assisted dying practitioner)
- 790. Designed safe access zones may include areas within the curtilage of the premise (e.g.: the office of the Jersey Assisted Dying Service) or the building in which the premises is located (e.g.: Jersey General Hospital if the Jersey Assisted Dying Service is located in the hospital) or areas that are not within the curtilage (for example, roads, pavements, open space to which the public have access)
- 791. The prohibited acts, which it would be an offence to commit may include:

- a. Obstructing (i.e,. putting obstacles in the way) or impeding (ie. blocking a person) a person from accessing, or providing, any part of the assisted dying process, where it is legitimate for that person to provide that part of the assisted dying service
- causing harassment, alarm or distress to person who is accessing any part of the assisted dying process (e.g.: a person who is attending an assessing doctor for the purpose of having an assisted dying assessment) or is providing any part of the assisted dying process (for example, the assessing doctor providing that assessment)
- c. influencing a person's decision to access or provide the Jersey Assisted Dying service, or any part of the assisted dying process (for example, shouting threats in a safe access zone)
- 792. The prohibited acts can be acts against a person accessing or providing the assisted dying service or to any other person who is in the premise for any other purpose whether or not that is related to assisted dying (for example, a patient attending an appointment at a GP surgery where an assisted dying practitioner works)
- 793. The acts may be intentional (ie. the person committing the act may intend to cause the person having an assisted death, or the assisted dying practitioner alarm) or may not be intentional but have been undertaken recklessly and in such a manner as to have the same effect.
- 794. Clearly there are some premises which may need to be designated as safe access zones at speed (for example, if anti-assisted dying protestors are obstructing or impeding access to private home where a resident is having an assisted death). The law drafting officer is therefore asked to consider whether the Minister should be provided the power to designate safe access zones via Order. It is envisaged that, if there were an Order making power, the Minister would need to:
  - a. determine the premises and specific boundary around that premise to be designated
  - consult any such persons as the Minister is required by Regulations to consultant, in addition to any other person or entity that the Minister determines should be consulted
  - c. determine and provide for any associated timeframe for the designation. This could be:
    - a 'standing' designation i.e., the area is a safe access zone until any such point that the Minister, by Order, determines is not a safe access zone (for example, if access it continually impede to a GP's surgery where an assisted dying practitioner also works as a GP)
    - a time limited designation i.e., an area outside the home of a person who has an assisted death
- 795. Clearly, the Minister may only designate an area a safe access zone if the Assembly determines, by Regulations, to introduce safe access zones for assisted dying, and provide for a power of the Minister to make such designations by Order.

# **11.** Appeals

This section outlines the proposed appeals process.

- 796. Whilst most jurisdictions do not provide for an appeal process within their assisted dying legislation (an exception being some Australian states via Administrative Tribunal), the Jersey assisted dying law will provide for a right of appeal to the Court, in part to help support public confidence in the assisted dying process.
- 797. The appeals process is in addition to the ability of a person to request a second opinion (see section *Second opinion request*), make a service complaint (in accordance with the Committee's complaints policy) or raise a safety concern (in accordance with the Committee's safety concern procedures).

Note: all references to 'failure' in this section should be read as 'failure or a perceived failure'

2 working day requirement where assisted dying request is approved

- 798. The law will provide that there must be a minimum of 2 working days between request approval and the administration of the assisted dying substance. The 2 working days' period will provide an opportunity for a person who is entitled to appeal to make an application to appeal. It is acknowledged that this is a short period of time, but it aims to strike a balance between giving time for people with a special interest to make an application to appeal (see *Making an appeal* below), whilst not significantly impeding the assisted dying process where the person wishes to proceed.
- 799. For the purposes of clarity:
  - a. the day on which the Coordinating Doctor signs the Administrative Review Form thereby giving request approval is Day 0
  - b. the next working day is Day 1 (If Day 0 is a Saturday or Sunday, Day 1 is the Monday or, if the Monday is a Bank Holiday, Day 1 is the Tuesday)
  - c. the following working day is Day 2
  - d. the administration of the substance can then be on Day 3 (or any other subsequent day). Day 3 can be a non-working Day (ie. it can be a Saturday, Sunday or Bank holiday).
- 800. Where both the Coordinating Doctor and Independent Assessment Doctor are of the opinion that the person has a life expectancy of 14 days or less:
  - a. the 2 working day requirement does not apply
  - b. there would be no right to appeal.

801. The rationale for this being that if a person is at the very end stage of life, this would either unduly prolong their suffering and/or it is likely that the person would die anyway, prior to the appeals process concluding.

# 2 working day requirement where assisted dying request is refused

802. The minimum 2 working days is not relevant where an assisted dying request has been refused (regardless of when in the process it was refused, as the process will have stopped). Only the person requesting an assisted death, or their agent can appeal when a request is refused. The timeframe for making an application to appeal against refusal is 28 days.

### Making an appeal

- 803. All appeals will be made to the Royal Court, which will sit as the Inferior Number to make a determination.
- 804. The law will state that an application to appeal must be made within 28 days of the decision being made and the relevant form being signed and dated to confirm the decision. This time period is in line with other tribunal processes within Jersey, and with other assisted dying appeals processes, such as South Australia.<sup>60 61</sup> For the purpose of clarity:
  - the day on which the Coordinating Doctor signs the Refusal of Request form or Administrative Review Form thereby giving request approval or refusal is Day 0
  - b. the following day is Day 1 (regardless of whether it a working or not working day)
  - c. the day by which the application to appeal must be made is Day 28.
- 805. The following people may appeal:
  - a. the person who has requested the assisted death or an agent of the person who has requested the assisted death i.e., someone who the person has asked to act on their behalf ("the person/agent"); or
  - b. any other person who the Court is satisfied has a special interest in the care and treatment of the person ("person with a special interest")
- 806. The person with a special interest may, for example, be a family member, close friend or other attending practitioner or carer. This cannot include an unconnected third party (such as a representative of a lobby group) who is appealing on the basis that they do not support assisted dying.

<sup>&</sup>lt;sup>60</sup> For example - Charities (Appeals – Reasons and Time Limits) (Jersey) Order 2020 (jerseylaw.je)

<sup>&</sup>lt;sup>61</sup> <u>Voluntary Assisted Dying Act 2021 (legislation.sa.gov.au)</u> – Part 7 85 (3)

- 807. It is up to Court to determine if the person making the application for appeal is eligible to do so. Being a relative of the person accessing assisted dying does not mean the applicant is automatically considered to have a special interest (for example, a relative who is not closely connected i.e., a second cousin OR a relative where the Court is satisfied that they are appealing based on their principled objection to assisted dying OR where the Court is satisfied as to longstanding estrangement)
- 808. Note: It is acknowledged that a person with special interest can only appeal if they are aware of the assisted dying request in the first instance. Whilst the assessing doctors will encourage persons requesting an assisted death to involve and / or inform their family and friends the person may have chosen not to do so; hence the appeal provision has limitations.

### Decision by Coordinating Doctor to approve or refuse an assisted dying request

### Grounds for appeal: the person / their agent

- 809. The person / their agent can appeal a decision of the Coordinating Doctor not to provide request approval (i.e., following a Refusal of Request at any step in the process or following a decision of the Coordinating Doctor to not provide request approval at the end of Step 5) but they cannot appeal a decision of a Coordinating Doctor to provide request approval.
- 810. The person / their agent can appeal a decision of the Coordinating Doctor or Administrating Practitioner to refuse an assisted dying request. They may appeal:
  - a. one or more of the following reviewable decisions:
    - that the person was not aged 18 or over at the time of making their First Formal Request, if the person contests this is not correct
    - that the person had not been ordinarily resident in Jersey for at least 12 months at the time of making their First Formal Request, if the person contests this is not correct
    - the person's wish was not voluntary, clear, settled and informed at any point in the process (including after Final Review at Step 7), if the person contests this is not correct
    - the person does not have capacity to make an assisted dying decision at any point in the process (including after the Final Review at Step 7), if the person contests this is not correct
  - b. on the ground that there was a failure by the Coordinating Doctor or any involved professional to make determinations or act in accordance with the law (i.e., service failing or maladministration).

- 811. A person / their agent cannot appeal a decision of the Coordinating Doctor to refuse the person's assisted dying request on the grounds that an assessing doctor (whether or not that assessing doctor is the Coordinating Doctor) determined that the person does not meet any aspect of the health eligibility criteria.
- 812. There is no appeal on the grounds of health eligibility criteria because detailed consideration of matters related to diagnosis, prognosis and treatment will have been undertaken during the assessment process.

For clarity, a person / their agent cannot appeal because they believe there are compelling grounds not to meet the criteria i.e., they cannot say "I haven't been resident for 12 months / I am not aged 18 or over / I do not have a termination illness etc, but I believe there are compelling reasons I should be allowed to have an assisted death".

- 813. As above, the person / their agent can also appeal on the ground that there was a failure by the Coordinating Doctor <u>or any involved professional</u> to make determinations or act in accordance with the law (i.e., service failing or maladministration).
- 814. However, this would not include any failure by a relevant professional providing a supporting opinion or assessment, as they are not making any determination on the person's eligibility for assisted dying. There may, however, be an appeal against a failure by an assessing doctor in relation to requesting or not requesting a supporting opinion or assessment, or in them having regard to an assessment/opinion in their determination of eligibility.

### Appeals by a person with a special interest

- 815. A person with a special interest can appeal a decision of the Coordinating Doctor to provide request approval at end of Step 5, but they cannot appeal a decision of a Coordinating Doctor to refuse an assisted dying request (regardless of when in the process that request is reviewed).
- 816. A person with a special interest cannot appeal a decision to provide request approval at any other stage of the process, as the assessment process is still ongoing. During previous steps of the process there are alternative options for raising concerns or challenging decisions, prior to appealing to the Courts. For example:
  - a. the assessing doctor must seek the opinion of connected persons (where consent has been obtained) if they are unable to determine that the person's wish is voluntary, clear and settled during the assessment process. This

provides an opportunity for the person with special interest to raise concerns / objections with the assessing doctor

- b. the assessing doctor may seek the opinion of relevant professionals during the assessment process, for example a social worker who may advise on family dynamics or the presence of coercion (where consent has been obtained)
- c. the person with a special interest may make a service complaint (in accordance with the Committee's complaints policy)
- d. the person with a special interest may raise a safety concern (in accordance with the Committee's safety concern procedures).
- 817. A person with a special interest may appeal:
  - a. one or more of the following reviewable decisions:
    - i. that the person is aged 18 or over at the time of making their First Formal Request, and the appellant contests this is not correct
    - ii. that the person has been ordinarily resident in Jersey for at least 12 months in the period immediately before the person makes their first formal request for an assisted death, and the appellant contests this is not correct
    - iii. that the person's wish is voluntary, clear, settled and informed, and the appellant contests this is not correct
    - iv. that the person has capacity to make an assisted dying decision, and the appellant contests this is not correct
  - b. on the ground that there was a failure by the Coordinating Doctor or any involved professional to make determinations or act in accordance with the law (i.e., service failing or maladministration).
- 818. There is no appeal on the grounds of health eligibility criteria because detailed consideration of matters related to diagnosis, prognosis and treatment will have been undertaken during the assessment process.

Suspension of the process where an appeal is lodged by a person with special interest

- 819. The assisted dying process will be suspended where an appeal is lodged by a person with special interest at the end of Step 5.
- 820. The assisted dying process will be suspended until a determination has been made or the application to appeal is withdrawn.

821. In the event of an appeal by the person/their agent against Request Refusal or failure to act in accordance with the law, the process would already have stopped, so there is no requirement to suspend.

# Outcome of appeal

- 822. Following an appeal, the law will set out that the Court may determine that:
  - a. at the time of making the first request, the person had been ordinarily resident in Jersey for a period of at least 12 months; or
  - b. at the time of making the first request, the person had not been ordinarily resident in Jersey for a period of at least 12 months; or
  - c. at the time of making the first request the person was aged 18 or over, or
  - d. at the time of making the first request the person was not aged 18 or over,
  - e. the person has decision-making capacity in relation to assisted dying; or
  - f. the person does not have decision-making capacity in relation to assisted dying; or
  - g. the person has a voluntary, clear, settled and informed wish to end their own life; or
  - h. the person does not have a voluntary, clear, settled and informed wish to end their own life; or
  - i. there was a failure to make determinations or act in accordance with the process set out in law (i.e., service failing or maladministration); or
  - j. there was not a failure, to make determinations or act in accordance with the process set out in law (i.e., service failing or maladministration).
- 823. If the person's / agent's appeal related to a reviewable decision / decisions and the appeal was:
  - not successful, the Coordinating Doctor's / Administering Practitioner's refusal decision stands (whether it was not successful on all matters or just one matter)
  - b. successful, the Coordinating Doctor's refusal decision is overturn (providing it was successful on all matters)
- 824. Where the Coordinating Doctor's / Administering Practitioner's refusal decision is overturned, the process will re-commence and will automatically move to the next Step (assuming the Person has signed/ signs the Step Transition form, where required).
- 825. For the purposes of clarity, the Court is making a decision as to whether the Coordinating Doctor's / Administering Practitioner's refusal decision was correct at the point at which it was made. Once the process recommences, the Coordinating Doctor and / or Administering Practitioner may make new refusal decision and that refusal decision may relate to the same matter. For example, during the First Assessment the Coordinating Doctor may determine a person does not have capacity, and refuse the person's request. The person may appeal and be found by the Court to have capacity.

The process may then recommence and during the Second Assessment, the Independent Assessment Doctor may then find the person does not have capacity, and the basis of that assessment the Coordinating Doctor may again refuse the person's request – which may result in further appeals on the same matter.

- 826. If the person's / agent's appeal related to a failure to make determinations or act in accordance with the process set out in law and the appeal was:
  - a. not successful the Coordinating Doctor's refusal decision stands
  - b. successful, the Coordinating Doctor's refusal decision does not stand.
- 827. If the appeal was successful, the Court may determine that:
  - a. the step in the process in which the failure to made determinations / act in accordance with law should be repeated before proceeding onto the next steps (For example, if the Court determines that the Independent Assessment was undertaken by an assessing doctor who was conflicted, the Court may determine that Independent Assessment may be repeated)
  - b. the step in which the failure to made determinations / act in accordance with law happened does not need to be repeated before proceeding onto the next steps
- 828. In repeating the step, and in proceeding through the other steps in the process, it may be that the person is still found not to meet the eligibility criteria and their request may still be refused (for example; if the Court determines that the Coordinating Doctor should have sought a supporting capacity assessment during the First Assessment (Step 2) and in repeating Step 2, the professional undertaking the supporting capacity assessment finds the person not to have capacity, the Coordinating Doctor may still refuse the person's request).
- 829. The law should provide that the Court may determine whether the Step to be repeated is undertaken by the same professional who previously undertook that step, or a different professional, but in doing so the Courts should have regard to the resources of the assisted dying service (ie. if it is particularly complex request, which has already involved second opinion doctors, it may be that all registered assessing doctors have already been involved in the case). The law should not, therefore, prevent the same professional repeating the Step.
- 830. Where, post appeal, the Coordinating Doctor's refusal decision still stands, this does not preclude the person from making another First Request if the person's circumstances change in any other way that would result in them meeting all the eligibility criteria.
- 831. If the person with a special interest's appeal related to a reviewable decision and it was:

- a. not successful, the Coordinating Doctor's approval stands (provided it was not successful on all matters that were appealed)
- b. successful, the Coordinating Doctor's approval decision is overturned (even if it was only successful on one matter)
- 832. If the person with a special interest's appeal related to a failure to make determinations or act in accordance with the process set out in law and the appeal was:
  - a. not successful, the Coordinating Doctor's approval decision stands, the suspended process is 'unsuspended' and the person may proceed to the next step
  - b. successful, the Court will decide what steps, if any, need to be repeated. The Court may determine that:
    - no steps need to be repeated because, even though there was failure of process it is still evident to the Court that the person is eligible
    - only the step in which the failure occurred needs to be repeated and / or
    - any steps before or after the failure occurred.
- 833. The law should provide that, if a step / steps are to be repeated the Court may determine whether the Step /s to be repeated is undertaken by the same professional who previously undertook that step, or a different professional, but in doing so the Courts should have regard to the resources of the assisted dying service (i.e., if it is particularly complex request, which has already involved second opinion doctors, it may be that all registered assessing doctors have already been involved in the case). The law should not, therefore, prevent the same professional repeating the Step.
- 834. A determination must be made within 7 working days of the application being made.
- 835. The decision of the Royal Court will be final. There will be no further right of appeal.
- 836. If the person dies prior to Court making it determination (not as a result of assisted dying, as process will have stopped or been suspended), the appeal application is withdrawn.
- 837. The law will provide for the making of Court Rules related to assisted dying appeals. This may include matters relating to:
  - a. provision of further evidence, information or testimony and associated timeframes
  - b. notification procedures at the point at which an appeal application is submitted, as it is imperative that the assisted dying process is immediately suspended until the Court has ruled.

# **12.** Offences

Suicide and assisting suicide in Jersey

### Assisted dying is not suicide

- 838. For the purposes of the assisted dying law, an 'assisted death' will only relate to the death of a person who has requested, been assessed and approved for assisted dying and dies as a result of the self-administration or administration of an assisted dying substance, carried out in accordance with the law.
- 839. The law will set out that a person who dies as a result of the self-administration / administration of the assisted dying substance, carried out in accordance with the law, does not die by suicide.
- 840. The principle that assisted dying is not suicide is provided for in many of the Australian assisted dying laws including Western Australia, New South Wales, Queensland.<sup>626364</sup>

## Suicide is not an offence

- 841. In Jersey law, as matters currently stand there is a lack of clarity as to the legal provisions associated with suicide and assisting suicide.
- 842. Suicide was previously treated as a crime in Jersey under customary law, but practice has evolved, and the Courts have ceased treating suicide as a crime. The Homicide (Jersey) Law 1986 refers to the offence of "aiding, abetting, counselling or procuring a person's suicide" but it is doubtful whether there can be an offence of "aiding, abetting" etc. if suicide itself is no longer an offence.
- 843. Having consulted with the Attorney General, it is proposed this uncertainty is addressed and that the law should clarify that suicide (taking one's own life) is not an offence. See section 1 of the UK's 1961 Suicide Act.<sup>65</sup>

# Creation of the offence of encouraging or assisting suicide

- 844. At the same time as amending the law to explicitly clarify that suicide is not an offence, the law should also be amended to clarify that an act capable of encouraging or assisting the suicide or attempted suicide of another person is an offence. This clarity is required, given the uncertainty created by the current legislation, including the drafting of the Homicide (Jersey) Law 1986.
- 845. Such an offence would be broadly in-line with section 2 of the UK's Suicide Act 1961.<sup>66</sup> The UK Suicide Act was amended in 2010 by the Coroners and Justice Act 2009, this updated the language from "aids, abets, counsels or procures" to "encouraging or assisting" the suicide or attempted suicide of another person.<sup>67</sup>

<sup>&</sup>lt;sup>62</sup> Voluntary Assisted Dying Act 2019 - [00-00-00].pdf

<sup>63</sup> Voluntary Assisted Dying Act 2022 No 17 - NSW Legislation

<sup>&</sup>lt;sup>64</sup> Voluntary Assisted Dying Bill 2021

<sup>65</sup> Suicide Act 1961

<sup>66</sup> Suicide Act 1961

<sup>&</sup>lt;sup>67</sup> Coroners and Justice Act 2009 - Explanatory Notes

- 846. The rationale is to clarify that whilst a death carried out in accordance with the assisted dying law is not an offence (i.e., it is permitted in law) any person who assists or encourages another person to take their own life, <u>in any other way</u> would be committing an offence (with prosecution for the offence being subject to the Attorney General's code on prosecution decisions see below).
- 847. Currently if a person assists the suicide of another person in Jersey, it is not clear if a specific offence committed, but it is conceivable that depending on the particular facts, that a person assisting another person to take their own life could be charged under one of the offences of the Homicide (Jersey) Law 1986 for example murder or manslaughter.<sup>68</sup>
- 848. Updating the law to create an explicit offence for anyone who encourages or assists suicide in any way other than with the assisted dying framework, would include for example:
  - a. buying lethal drugs for a partner with the intention that they will take them to end their life (this is an area of potential increased risk given the availability of some lethal drugs on-line, and associated prosecutions relating to supply of lethal drugs in jurisdictions such as Canada)
  - b. a doctor prescribing a person with medication, with the knowledge that the person intends to take the medication to end their own life
  - c. it could also, potentially include supporting a person to travel to another jurisdiction such as Switzerland, to have an assisted death
- 849. Under the offence of encouraging or assisting the suicide of another person it is intended that a person would commit an offence whether or not a suicide, or an attempt at suicide, occurs so for example, a person would commit an offence if they sent lethal pills to a person, but those pills were subsequently lost in the post.
- 850. A person would also commit the offence even if the person attempting suicide is not known directly to them for example, the author of a website promoting suicide who intends that one or more of their readers will commit or attempt to commit suicide is guilty of an offence, even though they may never know the identity of those who access the website.
- 851. Law drafting officers are asked to consider whether the explicit creation of such an offence would be most appropriate as an amendment to the Homicide (Jersey) Law 1986. Or if this not considered to be the most appropriate place, then whether the Homicide (Jersey) Law 1986 should be amended to remove reference to the offence of "aiding, abetting, counselling or procuring a person's suicide".
- 852. Conversations with Law Officers indicate that the Attorney General will consider issuing a Code on the decision to prosecute in relation to the newly defined offence of assisting or encouraging suicide. <sup>69</sup> In doing this, regard would be given to the UK's Director of Public Prosecutions guidance, which includes setting out certain limited

<sup>&</sup>lt;sup>68</sup> Homicide (Jersey) Law 1986

<sup>&</sup>lt;sup>69</sup> <u>Code on the decision to prosecute (Law Officers' Department) (gov.je)</u>

circumstances where pursuing a prosecution for assisting or encouraging suicide may not meet the 'evidential' or 'public interest' tests. Factors tending against prosecution in the UK guidance include, for example<sup>70</sup>:

- a. the victim had reached a voluntary, clear, settled and informed decision to commit suicide;
- b. the suspect was wholly motivated by compassion;
- c. the actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance
- d. the suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide.

# Offences under the assisted dying law

853. In jurisdictions where assisted dying is permitted, there are two broad approaches to offences under the law:

*Approach 1:* assisted dying is treated in law as an exception to existing criminal offences such as homicide. This means that a medical practitioner who supports a person's assisted death:

- *a.* would not be committing the offence of homicide if the assisted death complied with the assisted dying law
- *b.* would be committing homicide if the assisted death did not comply the assisted dying law.

This is the approach in the Netherlands, Belgium and Luxembourg.

*Approach 2:* this mirrors the first approach (i.e. outside of the assisted dying law, existing offences will apply) but also creates criminal offences for specific conduct under the assisted dying legislation. This is the approach used in most other jurisdictions, including Canada, New Zealand, all Australian states, and is the approach proposed for Jersey.

- 854. It is proposed that this approach is adopted in Jersey and the creation of additional offences is proportionate to the new roles and permissions created by an assisted dying law. It is an important safeguard, whereby the penalties act as a deterrent for any person who might intentionally act outside of the legislation.
- 855. It is proposed that the law will set out a number of offences for those who do not act in accordance with the law (as described below). The offences would apply to any person which could include professionals or, for example, family members.

<sup>&</sup>lt;sup>70</sup> <u>Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide | The Crown</u> <u>Prosecution Service</u>

#### Offences under the assisted dying law

#### Unauthorised administration of assisted dying substance

- 856. A person who is not authorised to do so must not:
  - a. administer an assisted dying substance to another person; or
  - b. support a person to administer an assisted dying substance to another person; or
  - c. support a person to self-administer an assisted dying substance.
- 857. The assisted dying substance is the substance (or combination of substances) used to bring about a person's assisted death. The assisted dying substance may be a drug or medicine or may include a drug or medicine which is used for other purposes relating to care or treatment of people (for example a painkiller or sedative). Clearly this offence should be cast not to include the legitimate use of those drugs and medicines.
- 858. A person is only authorised to administer the assisted dying substance if they are the Administering Practitioner, and conditions below have been met.
- 859. A person is only authorised to support administration of the assisted dying substance if they are the Administering Practitioner or administration witness or other suitably qualified person who is supporting administration under the direction of the Administering Practitioner (see paragraph 702 & 706 of core instructions), and the and conditions below have been met. Supporting administration could include, for example preparing the assisted dying substance in advance of administration or preparing for administration of the substance (for example, set up IV lines).
  - a. For clarity, a Pharmacy Professional may also be involved in the preparation of the assisted dying substance, as part of their role in preparing and dispensing the assisted dying substance or as a suitably qualified person who is supporting administration under the direction of the Administering Practitioner at Step 7.
- 860. <u>A person can only support</u> a person to self-administer an assisted dying substance if they are one of the following, and the conditions set out below have been met:
  - a. the Administering Practitioner, or
  - b. administration witness or other suitably qualified person who is supporting self-administration under the direction of the Administering Practitioner, or
  - c. a family member or loved one of the person who is self-administering the substance, but only where they are supporting self-administration under the direction of the Administering Practitioner (see paragraph 702-703 of core instructions).

- 861. The conditions which must be met are:
  - *a.* that the Administering Practitioner must have signed the Final Review Form and Consent form, declaring that:
    - they are satisfied to the best of their knowledge that the person's assisted dying request has been assessed and approved in accordance with the law
    - that they, the Administering Practitioner has undertaken all necessary checks at final review stage, and are satisfied that:
      - the person has capacity and continues to have a voluntary, clear, settled and informed wish to proceed, or
      - the person does not have capacity but has previously made a Waiver of Final Confirmation of Consent
    - that they, the Administering Practitioner, has given due consideration to the arrangements set out on person's Assisted Death Care Plan, and,
    - that they, the Administering Practitioner is now satisfied that they may proceed to administering the substance / supporting self-administration of the substance
  - b. that the administration / self-administration is taking place immediately proceeding the making of the Administering Practitioner's declaration.
- 862. For the purposes of clarity, no person, including the Administering Practitioner, may administer / support administration of the assisted dying substance at any time other than immediately after the making of the Administering Practitioner's declaration, even if the person has given their consent to do so.

# Inducing a person to make, or revoke a request or decision for, assisted dying

- 863. A person must not, dishonestly or by coercion, induce another person to make, or revoke (withdraw), an assisted dying request.
- 864. This would include inducing a person to make or revoke:
  - a. A First Formal Request for assisted dying
  - b. A Second Formal Request for assisted dying
  - c. a decision to have an assisted death:
    - i. when the person signs the final Step Transition Form at end of the Administrative Review process (end of Step 5)
    - when final consent is given by the person, with the person's capacity to make the decision being assessed during the Final Review (during Step 7)

- 865. This would not include:
  - a decision to proceed to the next step in the assisted dying process (a decision to progress is made when the person signs the Step Transition Form); OR
  - b. a decision to agree arrangements for their assisted death end (arrangements for an assisted death are agreed during Step 6)
- 866. The rationale for this being that the formal requests and decisions to have an assisted death are clear points in the process where a request or decision for an assisted death are made and confirmed. However, the decision to move to the next step in the process or agreeing arrangements for an assisted death are matters of process, rather than clear decision-making points that articulate a person's wish for an assisted death. This may, for example, be completely legitimate for loved one to encourage the person to make decision to proceed or not to proceed, if they believed doing so was supportive of that person.

#### Making a false or misleading statement or declaration

867. A person must not make a statement or declaration in a form or other document, as required to be made under the assisted dying law, that the person knows to be false or misleading in a material particular.

#### Falsifying a document:

868. A person must not knowingly falsify a form or other document required to be made under the assisted dying law.

#### Acting as an assisted dying practitioner when not registered:

- 869. A person must not act as an assisted dying practitioner or ADRMP unless they are registered with the Jersey Assisted Dying Service and their registration has not lapsed, been suspended or cancelled (for example, not acting as a Coordinating Doctor when they are not so registered). This includes not acting in a role for which they are not registered (for example, acting as a Coordinating Doctor when they are only registered as a member of the MDT).
- 870. A person must not act as Care Navigator unless they have completed the assisted dying training and have been engaged on a contract of employment or services by the Government of Jersey to so act.

# Prohibition of unauthorized use of expression "Jersey Assisted Dying Service", "Assisted Dying Practitioner" and related terms

- 871. An entity that is not the Jersey Assisted Dying Service:
  - a. must not hold itself out as, or refer to itself as the "Jersey Assisted Dying Service" or any other similar term; and
  - b. must not cause or permit another person to refer to the entity as a "Jersey Assisted Dying Service" or any other similar term, if it is not the Jersey Assisted Dying Service
- 872. A person who is not registered as an assisted dying practitioner with the Jersey Assisted Dying Service must not hold themselves out, or refer to themselves as being:
  - a. a Jersey Assisted Dying Practitioner, or
  - b. any other defined role set out in the assisted dying law (e.g.: Jersey Coordinating Doctor),
  - c. or any other similar term
  - d. and must not cause or permit another person to so refer to them as such.
- 873. Clearly a person may be a permitted assisted dying practitioner in another jurisdiction and may state as such but this must not do so in such as manner as to suggest that they are so registered in Jersey.
- 874. The policy intent is to prevent a person being misled that a person, who is not suitably qualified, trained and/or registered as an assisted dying practitioner/ ADRMP/Care Navigator, is an assisted dying practitioner/ ADRMP/Care Navigator in Jersey or connected to the Jersey Assisted Dying Service.

# Advertising and promotion

- 875. It is considered that an offence is required to prohibit the promotion or advertising of the Jersey Assisted Dying Service by written or broadcast advertisement or written communication in order that:
  - a. potentially vulnerable persons are not subjected to such promotion
  - organisations / individuals do not promote assisted dying in Jersey for their own gains or for reasons not in the public interest, for example advertising 'professional referrals' into the Jersey Assisted Dying Service for a fee or advertising services that support people to navigate the eligibility criteria
- 876. This should not include the following:

- a. Government of Jersey employees (e.g.: a policy officer) or person engaged by the Government of Jersey (e.g.: a freelance communications officer) promoting or making arrangements to promote the Jersey Assisted Dying Service and / or the assisted dying process when acting in accordance with their duties (for example, recruitment adverts for assisted dying practitioners; development and distribution of information flyers in public spaces, on-line information)
- b. a registered assisted dying practitioner, an ADMRP or Care Navigator, promoting their work in the Jersey Assisted Dying Service (for example, an assisted dying practitioner who is a GP stating this on the website of their GP surgery and inviting people to make appointments if they are seeking advice)
- c. a third party, for example a cancer charity or Citizen's Advice providing information to their service users / public that assisted dying is available in Jersey and to signpost them to further information
- d. any person, whether or not in the media, referencing the fact that assisted dying is legal in Jersey
- 877. For this reason, the law should provide a mechanism to amend any provisions relating to the unauthorized use of terms related to assisted dying, and the promotion or advertising of assisted dying. Including the option to amend, remove offences or provide for additional offences. Law drafting officers are asked to consider whether this is best achieved by a regulation making power, or if it could be achieved by an order making power.

Failure to inform the Jersey Assisted Dying Service of changes to professional registration or fitness to practise matter.

- 878. An assisted dying practitioner must inform the Jersey Assisted Dying Service of any changes to their registration status with either their UK professional registration body, or the JCC, including:
  - a. Any conditions or restrictions imposed on their registration, or the suspension or cancellation of their registration.
  - b. Any arising fitness to practise issues that may impact on their registration with their UK professional regulatory body, the Jersey Care Commission or the Jersey Assisted Dying Service. They must do so within 7 days of being notified by any relevant person of a pending investigation of fitness to practise.

Details of a specific assisted death or involvement of assisted dying practitioners not to be recorded or made public

- 879. It is intended that the law creates offences in order to protect the privacy of:
  - a. people accessing the Jersey Assisted Dying Service (e.g. persons who have made a formal request for assisted dying; persons who have had an approval for assisted dying; persons who have had an assisted death)
  - b. professionals involved in the assisted dying process (this includes involved professionals, care navigators and any professional who has provided a supporting assessment or opinion). This is to ensure that names / identities of professionals are kept out of the public domain so that there is no impact on either their safety or ability to carry out their role unless those professionals wish to release their own names.

# Persons who may commit an offence

- 880. It will be an offence for any person to unlawfully record or disclose information about an assisted death obtained by the person because of a function the person has or had under the assisted dying law.
- 881. Consideration was given as to making this an offence for <u>any person</u> to record or disclose information, however, this was discounted due to potential for:
  - a. criminalising the behaviour of grieving family members who inadvertently disclose information about an assisted death
  - b. causing confusion/censoring the behaviour of family members following the assisted death of a loved one, due to being uncertain what they can and cannot say about the death, which may have the effect of increasing stigma around assisted dying in the island
- 882. Therefore, a person may only commit an offence of disclosure of information if that person obtains the information having carried out or been requested to undertake:
  - a. **a function, as part of a specified role** e.g. an assisted dying practitioner, ADRMP or Care Navigator
  - an activity as requested by a person who carries out a function as part of a specified role under the assisted dying law – for example, a professional who has provided a supporting assessment or opinion at the request of an assessing doctor
  - c. a function related to the general provision of assisted dying, in accordance with the assisted dying law – e.g. chair/member of the Assurance and Delivery Committee or the Assisted Dying Review Panel
  - d. an activity as requested by a person who is undertaking function related to the general provision of assisted dying, in accordance with the assisted dying law e.g. a person who, as a result of their role has been requested to undertake an activity on behalf of the Assurance and Delivery Committee

- i. an example of this would be if an HCS staff member in the Quality and Safety team was required to audit information in relation to a service complaint against the Jersey Assisted Dying Service if that person were to record or publicly disclose details about a specific assisted dying practitioner, that would be an offence
- 883. a person who is undertaking a function related to the general provision of assisted dying, in accordance with the assisted dying law, may include the Minister or a person acting on behalf of:
  - a. Jersey Assisted Dying Service
  - b. Assurance and Delivery Committee
  - c. Assisted Dying Review Panel
  - d. the Jersey Care Commission
  - e. the Courts (with regard to the appeal process)
- 884. The inclusion of the Courts in the above list is intended to ensure, for example, that a professional directed by the Court to undertake an assessment of the person as part of the appeal process would have the same confidentiality requirements placed on them as a relevant professional requested to provide an assessment by an assessing doctor (e.g. as per paragraph 882b).

#### Information that must not be disclosed

- 885. This is intended to include information about the person accessing assisted dying or any health and care professional involved (whether or not they are an involved professional, a Care Navigator or professional providing an additional assessment or opinion). For example:
  - a. a Care Navigator cannot disclose the name of the person who has requested an assisted death to another person where it is not a requirement of the law (i.e., the Care Navigator needs to disclose the person's name to a Coordinating Doctor) or the appropriate information sharing consents are not in place)
  - b. an Administration witnesses cannot publish photographs of the Administrating Practitioner taken during the administration of the substance.
- 886. This means a person must not record the details or publicly disclose the details by publishing or broadcasting the information in the media, through social media or any other source of communication that may be widely accessible.
- 887. However, it is not an offence to make a record or disclose personal information:

- a. for a purpose under the assisted dying law, for example, where information is recorded in an approved form
- b. if a court or tribunal requires a person to produce documents or give evidence
- c. if a person is authorised or required by law to record or disclose the information.
- 888. The offences outlined above are in addition to the obligations of non-disclosure of personal information imposed on health and care professionals under other laws, such as the Data Protection (Jersey) Law 2018.
- 889. Specifically, a person must not record or make public the following matters in relation to a specific assisted death:
  - a. the method and mode by which the assisted dying substance was administered and other details of the assisted death, for example the time taken to die or if there were any medical complications
  - b. details of the prescription and drugs/medications used in the assisted dying substance administered to the person/ self-administered by the person
  - c. the name of the person who administered the assisted dying substance or assisted the administration of the assisted dying substance, and/or the administration witness
  - d. any other information related to the assisted death that is not publicly available
- 890. Specifically, a person must not record or make public the following matters in relation to any health and care professional involved in assisted dying (whether an involved professional, a Care Navigator or professional providing an additional assessment or opinion).:
  - a. that a person is or has been engaged by the Jersey Assisted Dying Service as either:
    - i. an assisted dying practitioner
    - ii. a Care Navigator
    - iii. a professional providing a supporting assessment or opinion
  - b. details of a person's involvement in assisted dying in Jersey including:
    - i. what role(s) they are registered to undertake
    - ii. their activity in the service for example the number of assisted deaths they have been involved in
  - c. any other information related to the person regarding their involvement in assisted dying in Jersey that is not publicly available

- 891. This does not apply the information is disclosed with the written consent of:
  - a. the person to whom the information relates (this could the person requesting the assisted death or the professional involved in the process); or
  - b. an executor or administrator of the estate of that person ("that person" may including the person who requested that assisted death, the involved professional, the assisted dying practitioner / Care Navigator).
- 892. The law should provide a Regulation making power to amend the description of the matters, including removing matters or adding matters that should not be recorded or made public.

# Details of the assisted dying substance Authorised Drug Regimen not to be made public.

- 893. In order to minimise risk of any 'copycat behaviour' or that the drugs that form the assisted dying substance are administered or self-administered by a person outside of the legal framework, in a combination and dosage that brings about death, the law should provide that it is an offence to make public details of the Authorised Drug Regimen for the assisted dying substance.
- 894. This means a person must not record the details or publicly disclose the details by publishing or broadcasting the information in the media, through social media or any other source of communication that may be widely accessible.

# Protections for person acting in accordance with the assisted dying law

- 895. A person does not incur criminal liability if that person in good faith and with reasonable care and skill, does a thing that:
  - a. is in accordance with the assisted dying law; or
  - b. they believe on reasonable grounds, is done in accordance with the assisted dying law
- 896. Reference to doing a thing, includes the omission to do a thing.
- 897. If acting as above (i.e., having acted in good faith, and with reasonable care and skill), that person would not be:
  - a. guilty of an offence under this law; or
  - b. liable for unprofessional conduct or professional misconduct; or
  - c. liable in any civil proceeding; or
  - d. liable for contravention of any code of conduct.

- 898. For example, if a Coordinating Doctor makes a determination that a person's request for assisted dying is a voluntary request, but subsequent evidence comes to light to indicate that the request was made under coercion from a third party, then the Coordinating Doctor would not be committing an offence if they demonstrated that during the assessment process they took the required steps, acted in good faith and had reasonable belief that the person was acting voluntarily.
- [Although in these circumstances the third party may have potentially committed the offence of 'Inducing a person to request, or revoke request for, assisted dying' if the coercion is evidenced.]
- 899. Furthermore, the law should set out that a health and care professional who does not administer life-saving or life sustaining medical treatment to a person:
  - a. who has not requested the life-saving or life sustaining medical treatment, and
  - b. who the professional reasonably believes is dying, and
  - c. who the professional knows has been administered or has been selfadministered - an assisted dying substance, and
  - d. where the professional reasonably believes that this administration was done in accordance with the assisted dying law
- 900. will not be:
  - a. guilty of an offence; or
  - b. liable for unprofessional conduct or professional misconduct; or
  - c. liable in any civil proceeding; or
  - d. liable for contravention of any code of conduct.
- 901. For clarity, the law should provide that it is not an offence for a health and care professional not to administer life-saving or life sustaining medical treatment to a person who has been administered the assisted dying substance, but the law should not prevent or impede a health and care professional from administering life-saving or life sustaining medical treatment to that person.
- 902. This would also not prevent a for a health and care professional from providing medical treatment only for the purpose of ensuring the person's comfort (i.e. the professional may administer medical treatment for comfort without also providing life-saving treatment). This is similar to provisions in Victoria's Voluntary Assisted Dying Act 2017 Article 81.<sup>71</sup>
- 903. The health and care professional referenced in the paragraphs above is a professional who is registered with the JCC and/or a UK regulatory body, and is authorised and

<sup>&</sup>lt;sup>71</sup> Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au)

trained to do so as part of their registration conditions (including ambulance paramedics).

904. The creation of specific offences in the assisted dying law will not affect the operation of existing criminal laws - individuals who act outside the legal framework for assisted dying will still be subject to prosecution for offences such as homicide.

# Note: Professional conduct

Whilst the law should provide for the criminal offences outlined above, it is also the case that registered health and care professionals may be subject to professional consequences if they participate in assisted dying and are non-compliant with:

- a. the assisted dying law
- b. registration requirements to act as an assisted dying professional
- c. all policies and guidelines related to assisted dying (including the protocols set out in the Assisted Dying Substance Administration Guidance which address matters related to medical complications associated with administration of the assisted dying substance)
- d. professional standards of the JCC and their UK professional regulatory body (e.g., GMC, NMC, GPhC, HCPC.)
  - including codes of ethics, codes of conduct and competency standards and including in relation to conscientious objection

This could include investigations into their professional conduct by either their professional regulatory body, the JCC, their employer or a combination of these. The law does not need to make any associate provisions related to this, other than the information sharing powers described in the instructions.

# **13.** Commencement

- 905. This section sets out the provisions in the Law which will need to be brought into force on registration in the Royal Court, in order to allow for the necessary set-up of the Service oversight functions during the implementation period, prior to the Law coming into full effect.
- 906. As noted in Section 1, it is anticipated that the registration of the Law in the Royal Court (following Privy Council review) will take place during 2026, with the full Law brought into effect by an Appointed Day Act in Summer 2027.
- 907. The provisions include matters relating to:

- a. setting up the Assurance and Delivery Committee and enabling the Committee to undertake preparatory functions, including:
  - i. development of training programme
  - ii. registration of assisted dying practitioners
- b. setting up the Jersey Assisted Dying Service
- c. registration of the Jersey Assisted Dying Service with the Jersey Care Commission

#### Establishment of the Jersey Assisted Dying Service

- 908. The requirement of Health and Social Services Minister ("the Minister") to make arrangements to establish an assisted dying service in Jersey (as per paragraph 145 of the core instructions)
- 909. The powers of the Assembly, by Regulation, to determine that the Assisted Dying Service should be provided by an entity other than HCS (see paragraphs 151 to 154)
- 910. The powers of the Assembly, by Regulation, to determine that the Minister, or provider of the Assisted Dying Service in the event that it is not the Minister, may levy a fee to access the Jersey Assisted Dying Service (see paragraph 148)
- 911. The requirement on the Minister to lay a report before the Assembly in the event the Minister is unable to establish an Assisted Dying Service (as per paragraphs 155 – 159).
- 912. The following functions of the Jersey Assisted Dying Service (as per paragraph 160) which need to be delivered / in train prior to commencement of the service
  - i. develop and publish information about assisted dying in Jersey both online and in printed formats, including the provision of accessible information
  - j. maintain the assisted dying practitioner register on behalf of the Assisted Dying Assurance and Delivery Committee and in accordance with any requirements of Committee or the law, or Order of the Minister
  - k. engage, the assisted dying practitioners and the Care Navigators who will support delivery of the assisted dying process

#### Establishment of the Assurance and Delivery Committee

- 913. The requirement on the Minister to establish the *Assisted Dying Assurance and Delivery Committee* as per paragraph 164.
- 914. The power related to the appointment of the Committee Chair and members, and the development and adoption of the Terms of Reference, as per paragraphs 176- 197.

# Preparatory functions to be undertaken by the Assurance and Delivery Committee

915. The following functions of the Assurance and Delivery Committee (as per paragraph 166), that are required to prepare for the full law coming into effect:

matters related to the establishment of the Jersey Assisted Dying Service, including:

- a. making arrangements for the development of the following, and approving and publishing the following:
  - information about the Jersey Assisted Dying Service. This information should be both online and in printed formats and include accessible information (i.e. information which can be read or received and understood by the individual or group for which it is intended) and alternative formats (for example, large print versions for those with visual impairments)<sup>72</sup>
  - Jersey Assisted Dying Service standards (for example, target maximum timeframes for the Service to undertake the assisted dying process or to respond to poor service complaints)
  - the retention schedule and retention arrangements for all records held by the Jersey Assisted Dying Service
  - non-professional guidance.
- b. making arrangements for the development of the following, approving the following and making available to relevant persons:
  - the assisted dying training programme (as per paragraphs 285 to 290)
  - the assisted dying refresher training programme
  - an Appropriate Conversations training programme
  - professional guidance required under the law
  - competency frameworks for all assisted dying practitioners and ADRMP (as per paragraphs 270 to 282)
  - the Assisted Dying Person Record system (see section on *Assisted Dying Person Record and Guidance,* paragraphs 376-380)
  - processes and standards for investigation and response to safety concerns, complaints relating to service standards, and whistleblowing to be made available to the public the process for making complaints against service standards, raising safety concerns and whistleblowing procedures
  - the Assisted Dying Declaration of Interests Policy (see section on *Registration Declaration and Specific Person Declaration*)

<sup>&</sup>lt;sup>72</sup> <u>NHS England Report Template 1 - long length title</u> – see NHS Accessible Information Standard specification for detailed description of accessible information and alternative formats

- c. making arrangements for the development and publication of all forms related to the assisted dying process, having consulted on the development of the forms with any entity the Committee or the Minister deems relevant.
- d. making arrangements to establish the register of assisted dying practitioners and ensuing maintenance of that register by the Jersey Assisted Dying Service (as set in paragraphs 266-267 and 283 and 291 to 320) and to provide the Committee with powers to suspend or remove a professional from the assisted dying register and to share or disclose information with any relevant entity (as per paragraph 175)
- e. making arrangements for the development and provision of systems that support involved professionals and Care Navigators (i.e., those who are directly involved in the assisted death) to process and reflect on the impact and emotions associated with assisting a person to die (for example, counselling / therapeutic de-briefing; peer support groups) (as per paragraph 322)
- f. making arrangements for the development of the authorised drug regimen, and then approve the regimen. In doing so the Committee must consult any organisation or body that the Committee deems relevant. This may include, for example
  - i. Chief Pharmacist
  - ii. the General Pharmaceutical Council
  - *iii. the Royal Pharmaceutical Society*
  - iv. the Medicines and Healthcare Products Regulatory Agency
- g. any other matters relevant to the establishment of the Jersey Assisted Dying Service as directed by the Minister

#### oversight of the Jersey Assisted Dying Service, including:

- h. establishing systems to compile data and monitor the following matters related to service safety, service quality and service usage / uptake and to undertake that monitoring:
  - compliance with the assisted dying law
  - compliance with the professional guidance
  - management and response to complaints
  - investigation and response to patient safety concerns or incidents or service risks
  - compliance with the Jersey Assisted Dying Services service standards

- data related to outcomes and numbers and profile of service users (see section on Annual report below)
- 916. Provide that the Committee may make arrangements for the development of professional guidance, other core documents and non-professional guidance as set out in paragraphs 167-174.
- 917. Provide that the Committee must prior the commencement of the Service, consult the Medical Officer for Health about matters relating to the annual report as set out in paragraph 205.
- 918. Provide that the Committee must prepare a report when required by the Minister or may prepare a report on any aspect of assisted dying– as set out in paragraph 208.
- 919. Provide for the establishment of an Assisted Dying Review Panel, including making arrangements for the recruitment of Panel members to be appointed by the Minister.
- 920. To include provisions for:
  - a. processes associated with the Panel to be provided for by Order of the Minister (see paragraph 721 and *'Note: Detail of matters to be provided for by Order'*,)
  - b. timeframes associated with the Panel's activities to be provided for by Order of the Minister (see paragraph 721 *and 'Note: Detail of matters to be provided for by Order'*)
  - c. development of Terms of Reference for the Panel as set out in in paragraph 730 731
  - d. the Minister to appoint members of the Panel as set out in paragraph 732

#### Functions to be undertaken by the Jersey Care Commission

- 921. Provide for amendments to the Regulation of Care Law (Jersey) Law 2014 (the "2014 Law") to allow for the Jersey Assisted Dying Service to register with the Jersey Care Commission (JCC), prior to commencing operations, as follows:
  - a. Schedule 1 of the 2014 law will be amended to include Jersey Assisted Dying Service as a defined regulated activity, including transitional arrangements that the Service may not operate until its provider and manager have registered with the JCC, and the JCC may undertake pre-registration visits (see paragraph 745)
  - b. Regulations introduced under Article 3(7)(a) of the 2014 Law which set out that the registered provider will be the Chief Officer of HCS or equivalent and the operational manager of the service will be required to register with the JCC (see paragraph 746)

922. Provide the powers of the Assembly, by Regulation, to bring amendments to this law and consequential amends to the Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018 and any other relevant legislation, to ensure potential service users cannot be denied access to care home and domiciliary care services on the basis of their views on assisted dying or a wish for an assisted death (see paragraphs 228 and 229).